

Invisible Children: A Study of Policy Exclusion

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Abstract

This research investigated a particular Government of India policy, known as the Integrated Child Development Scheme (or the ICDS). The ICDS operates amongst the poorer sections of the population in India, for pre-school children in the age range of 0-6 years. The ICDS policy, although it states that it is for 'all' children, does not in practice, address the question of disabled children. The research examined why and how such a major social policy in the country has omitted the disabled child from its agenda. It examined the socio-cultural attitudes towards disability in the Indian sub-continent and explored the wider historical, political and ideological framework in which Indian social policy for the disabled exists and within which the ICDS policy and practice may have become embedded.

Data collection included exploratory field visits; focus group discussions; triangulations by follow-up interviews; semi-structured interviews; analysis of historical and current documents.

The investigation concludes with the finding that various factors have led to disabled children being left out of the ICDS programmes. In the specific context of the ICDS, although it may have been the intention to include disabled children in the term 'all' children, there is a gap between policy stated and policy enacted, as the ICDS does not include them, in practice. The findings indicate that, due to ill-defined policy objectives during the policy formulation stage, policy remains silent on the issue, not clarifying that 'all' means disabled children as well. Implementation strategies for the inclusion of these children therefore are not worked out, which leads to the non-inclusion of disabled children from the programmes. In the wider context, the findings indicate that the national policy concerning disabled children lacks cohesion and does not give clear directives for the implementation of inclusion to take place. The Government's conceptualisation of disabled children is full of ambiguity and confusion: governmental reliance on voluntary organisations to deliver services ensures a micro-level coverage and indicates a lack of philosophical commitment to the integrated education of disabled children. Non-Government Organisations (NGOs) and their concentration on the delivery of services move the issue away from

a rights approach, leading to a disempowerment and depoliticisation of the disabled group. This takes the matter out of the public domain, making it a politically weak group and placing it within a charity framework. Negative attitudes, ignorance and a lack of awareness that prevails towards disability have also contributed to an overall ideological and cultural entrenchment in the subcontinent, contributing to marginalisation. The absence of a clear policy directive has left this segment of the population at a critical age out of the programmes of the ICDS.

Key words: Government, India, ICDS, policy, practice, disabled children, segregation, integration, NGOs.

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I would like to end by quoting the Indian poet, Tiravalluvar, whose statue sits outside the London School of Oriental and African Studies, and who said about acquiring knowledge, that 'what I have learnt can fill the palm of my hand, what I have yet to learn can fill the ocean'. Although it has been a very strenuous period in my life, it has been hugely intellectually exciting too; opening up new vistas for enquiry.

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Glossary

ICDS:	Integrated Child Development Services
AWW	Anganwadi worker
HRD	Ministry of Human Resource Development
MOW	Ministry of Welfare
IEDC	Integrated Education Department Centre.
DPEP	District Primary Education Programme
WCD	Women and Child Development (A Government of India reference)
NCERT	National Centre For Training and Educational Research
NIPCCED	National Institute for Public Co-operation and Child Development
NCTE	National Council for Teacher Education
DRC	District Rehabilitation Centre
EFA	Education For All
GOI	Government of India
ESCAP	Economic and Social Commission for the Asia Pacific.
UGC	University Grants Commission
Zilla Parishad	District level organisation
Gram Panchayat	Village level organisation

Anganwadi: Centres for delivery of package of services under ICDS in a village/urban slum. Literally a courtyard playgroup for children in the age group 0-6 run by anganwadi workers usually selected from the local village or local slum area.

B.M.C.: The Bombay Municipal Corporation, the local authority in Bombay to provide education, health, transport and other civic amenities like water, electricity, roads.

Balwadis: A child day care nursery for age group of 3 - 6.

Bustees/ Jhopadpattis: Other terms to describe slum-like conditions and people living not in proper concrete housing but in huts or shacks in a shanty town spread.

Chawls: Indian term for a slum in the cities. A common characteristic of all slums is substandard housing, lack of basic amenities such as water, sewage facilities.

Central Government: Refers to highest levels of Government under India's federal system that comprises of 29 States and Union Territories.

Indian terminology for stratification of society.

Scheduled Caste:

The four major castes in Indian society are the Brahmins, Kshatriyas, Kayastha and Shudras. The caste system was created five thousand years ago and was based on the principle of functions or trades – the highest were the teachers and educators known as the brahmins, the warriors or kshatriyas, trades-people or the kayasthas, and the cleaners or shudras. This was believed to be hereditary, a fixed class of society, generally divided into high and low. The term scheduled castes was based on the last category of people in this hierarchy. They are people who are socially, educationally and economically the backward classes of Indian society who were termed as ‘untouchables’ in the pre-independence days.

Scheduled Tribe:

The scheduled tribes basically live in the remote and inaccessible forest areas cut off from modern civilization. They have their own culture and dialects, which India has tried to safeguard. The main characteristics are tribal origin, primitive way of life, living in remote and not easily accessible areas, and general backwardness.

Other Backward Classes or the OBCs:

Other backward classes refer to the people who are not scheduled castes or scheduled tribes but for economic and other factors considered to be backward classes deserving special consideration.

The two most disadvantaged groups in Indian society are the scheduled caste and the scheduled tribes constituting 23.5% of the total population. The scheduled castes, the scheduled tribes and people from other backward classes have a high priority for social services as a part of India's positive discrimination programmes. The reason for being termed 'scheduled' is that various castes and tribes are listed in a 'schedule' to the Indian Constitution and according to which, are officially recognised as deserving special consideration due to their unfavourable position in Indian society since Independence (Naik1975).

Slum or peri-urban area: The slum phenomenon has been an outcome of industrialization and urbanisation. Due to unemployment in the rural areas there has been an influx of rural migration into urban cities. Characteristics of a typical slum in India are congestion, overcrowding, unplanned, unhealthy, unhygienic environment, without access to basic amenities such as water, sewage and drainage. People living in the slums belong mainly to the scheduled caste; some parts of the population may have tribal people from the scheduled tribe and there would be the OBCs as well. General characteristics are high levels of illiteracy, and beliefs in indigenous mores.

State Government: Refers to the Government of a particular State in India.

Bombay is referred to as Mumbai, a change introduced in the mid '90s, as it was felt by a particular political party that Bombay was too Western a term. However there

has been differing schools of thinking on this and some prefer the old name. In the study both names are used.

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Preface

It has been said that research cannot be a value free or a neutral activity, as we have our own value systems that can influence us (Clough and Barton 1995). Reflection on issues related to oneself and the research act are 'important determinants in providing a frame of reference about the researcher', thus giving the reader the chance to understand in what way a piece of research could be creating biases and introducing a situation where the researcher's neutrality could be questioned (Clough and Barton 1995). The constructs held by individuals are likely to involve a mixture of political, ethical, theoretical frameworks, which would have shaped the way an individual views life, and these then interact with the research act in a certain manner. It is important for the researcher, to demonstrate what kind of ideas he or she brings to the research act. What body of knowledge informs those ideas and how did they originate? What part does our own value system play in determining the stands we take? The idea being to engage critically with one's assumptions and the preconceptions connected with one's situation, which could act as bias; hidden values that the researcher may have, which make it difficult to be critical (Bines 1995). It is also important to articulate these, making one accountable and answerable, and give the reader a chance to decide whether the research has been affected by it or not. A 'reflective critique' (Bines 1995) of oneself, and a careful examination and sharing of one's personal and social constructs with the reader, is needed for an act of research to reduce bias (Bines 1995).

Professionally, I have been responsible for starting an organisation for disabled children in India, and have been working in the field of disability for 25 years. It has involved working closely with parents, with the Government, with other Non Governmental Organisations (NGOs) both at the national and international levels, and in various organisational, administrative, and technical areas.

On the personal side, my interest in the field of disability is part of a long standing concern for disabled children and their education, which began as a result of

move in the last twenty years from segregating children with disabilities to special schools to integrating them in ordinary schools. The paramount importance of integrating them in appropriate environments, suited to their special needs, has also been emphasised (Wedell 1982; Booth and Potts 1983; Hegarty 1984; OECD 1994). However, integration has been possible in the industrialised countries, because the education system has evolved over a period of time, and as awareness developed the disabled child, became mainstreamed into the normal system of education (Hegarty, Pocklington, with Lucas 1982; Wedell 1982; Cole 1989).

Today, the education of the disabled child has become statutory, and Acts of Parliament have been passed, entrusting the responsibility for providing services for handicapped people to the State. Legislation backed with fiscal support in some countries has empowered the disabled child and their families to seek legal redress if they find statutory services not complying with the law or discriminating against them. Today a vast network of rehabilitative services exists for the disabled child, which seeks to integrate them into society, as a matter of right and not charity (Cole 1989; OECD 1994; UNESCO 1995).

5.2 The National Scene

Equalisation of opportunity necessitates change, and intervention requires change at various levels. In India the fundamental questions relating to gender issues, disability and poverty confront us when prioritising services. The Government relies on voluntary organisations to set up basic facilities of education and treatment. The ground reality show that a vast majority of India's disabled population remain excluded from mainstream society (Burrett and Nundy 1994; Harriss-White 1995; Pandey and Advani 1995).

Historically, Indian documents show that right from 1944 the Education Commission emphasised that provisions for handicapped children should form an essential part of the national system of education and be administered by the Education Department (Sargent Report 1944). We find that in 1966 the Department of Welfare within the Ministry of Education became a separate Ministry called the

my daughter being born with cerebral palsy¹ in 1966. Not finding much understanding about her condition in the mid 1960s in India, we, (my husband, daughter and myself), moved to England. It was then that I began my professional life at the Institute of Education, University of London, where I studied to be a teacher for children with physical handicap. In 1969 the concept of integration was still in its infancy, and this may be the reason why students were not taken to observe any schools where integration was being practised; the teaching continued to be about disabled children in segregated special schools, and visits included some excellent special schools.

Very little was known in India about the special educational needs of children with cerebral palsy. This was one of the categories which was not included by the Ministry of Welfare (responsible for disabled children in India) amongst its classifications. On my return to India, together with a group of friends in 1972, I was able to set-up the first social and educational model for children with cerebral palsy combining education and treatment, under one roof. There are some photographs in Appendix 11. The organisation was called The Spastics Society of India.² In 1974, The Spastics Society of Eastern India was opened in Calcutta; in 1978, The Spastics Society of Northern India was launched in New Delhi and in 1982 and 1985, The Spastics Society of India, Bombay opened two branches in Bangalore and Madras. Each of the Societies is independent and they are well known for their innovative work for the disabled. Currently 16 of the 29 States of India have been able to replicate this model (See Bowley and Gardner 1980: 220 for more details).

Although the Spastics Societies³ had phenomenal outreach it was only the tip of the iceberg. The Government's own statistics for disability reported that 98 per cent of

¹ 'Cerebral Palsy' is caused by a brain lesion which is non-progressive and leads to impairment of functions in various areas. It represents a series of problems far more complicated than those typical of most other types of physical disabilities (Bax, M. et al, 1990).

² The map indicates the position of the Society and its services. The research site of Dharavi can also be seen.

³ This unfortunate terminology 'spastic' still lingers as it has not yet become a term of abuse in India, however, the Spastics Society is considering a change in the nomenclature.

Map 1 MAP OF MUMBAI (BOMBAY)
INDICATING THE POSITION OF THE SPASTICS SOCIETY'S
CENTRES AND THE RESEARCH SITE

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disabled people and children were out of the ambit of services (GOI 1994). They were in areas that would be difficult for voluntary agencies functioning in the metropolitan cities to reach.

All over the world there had been a shift away from special schools to regular schools. In Britain, the old language which labelled handicapped people as 'lame', 'defective', 'cripple' and later as sub-normal, epileptic, mentally handicapped had been abandoned and replaced by the new language, whereby youngsters with disabilities were described by broader more general terms such as 'children with special educational needs' (Wedell 1982; Evans and Varma 1989). Legislation backed by fiscal support now allowed children with special educational needs to study side by side with their peer group, giving them an opportunity to be a part of their community. Although various problems of inclusion still persisted, nevertheless, a majority of children with special educational needs were now a part of the normal school system. In the United States, The Education for All Handicapped Children's Act enacted in 1975, a major piece of legislation, mandated that free, equal and appropriate public education, must be provided between 3-21 years for children and people with special needs. This concept of normalisation in which handicapped children were to participate, was generally referred to as placement in the 'least restrictive environment' (Bruininks 1985). Recent years have seen the enactment of legislation in many countries: Sweden, Norway, Italy, United Kingdom, Denmark, France and Germany seeking integration or mainstreaming of children with special needs (Hegarty 1982). Today, in most of the developed countries, legislation has made integration a national policy and a mandate for children with any kind of handicap to be integrated, although in practice there is still segregation (Pijl and Meier 1991).

Meanwhile, while working in the slums of Dharavi, Asia's largest slum in Bombay, I observed that the ICDS, a pre-school nutrition and early education programme, was not including disabled children in their services. How did this happen? Why had the ICDS left out disability from their agenda? My own work with infants had taught me how crucial it was to intervene as soon as possible, to prevent secondary handicaps from happening. Questions, which now seemed urgent to have

answers for were: What had gone wrong in India? Why were the disabled still not State responsibility? Had we as professionals contributed to this situation?

I now felt that disabled children should be given equal opportunities and should not be removed from their peer group or their community. Special schools would be needed for a while for children with more severe difficulties until the whole system had evolved enough to understand all children. In India, given the problem of numbers, this may take time. There may be other impediments-however politically correct this may be, integrating all disabled children may not be the right paradigm for India.

I decided to re-examine my earlier stand that disabled children should be given services by voluntary organisations. I now believe that Government, as the main Trustee of a Nation, must play a major role in bearing responsibility for all its citizens, as so many Governments have done all over the world.

PART I

THE PROBLEM

1 THE RESEARCH STUDY

Introduction

Chapter 1 begins with the definition of disability as used in this thesis and understood in the Indian subcontinent, and moves on to present the rationale for the thesis, the research objectives, the frame of reference, the research question, concluding with the summary of chapters.

1.1 Definitions

Disability is a relative term, since different cultures define their norms differently. Concepts of disability are therefore situation bound, contextual and can be subjective (Ingstad and Whyte 1995; Pandey and Advani 1995; Harriss-White 1995). 'Economically oppressive and socially tyrannical and politically disenfranchising forms of work such as child labour and bonded labour are sometimes considered disabling' (Harriss-White 1995:2). The socially and economically disadvantaged child, living within a situation of grinding poverty, with no services, can be seriously disabled by its situation and by the environmental milieu. In a tradition bound society like India, stratified by caste, class, religion, rich and poor, male and female, social attitudes can disable a person (Alur 1988; Pandey and Advani 1995; Miles 1995; Harriss-White 1995). Disability can be regarded as taboo, a retribution for past sins committed, stigmatising a child, cutting across economic boundaries. Societal attitudes can be more disabling than the functional loss of a limb.

Handicap is the result of an interaction between an individual with impairment or disability and the environment. Barriers can be social, cultural or physical so that he

or she cannot fulfil his or her role in society, which means that a disabled person may be handicapped in one environment but not in another (Lagerwall and Tiroler 1995 see Figure 1: Handicap and Society).

Figure 1: Handicap and Society

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(Source: Lagerwall and Tiroler 1995)

Poverty and disability (disability here being referred to as a functional loss) are closely related (Narsing Rao 1990; Harriss-White 1995; Tiroler 1995). Poverty and disability have been described as a vicious circle. See Figure 2: Poverty and the Vicious Circle (Lagerwall and Tiroler 1995).

Figure 2: Poverty and the Vicious Circle (Source: Lagerwall and Tiroler 1995)

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As disability and definitions of handicap vary extensively in different cultures and environments, and as the thesis argues generally about policy and practice for all disabled children, regardless of any specific group, the term 'disabled children' is used, to include children with any type or any degree of disability. However, since the term 'disabled' can also be situational and context bound and having many connotations, disability as defined by an earlier WHO (1980) definition, and adopted by the Government of India (Aggarwal GOI 1993; Pandey and Advani 1995; Baquer and Sharma 1997) will be used.

The WHO definition of disability has been described within a three-tier definition consisting of:

- i) impairment: the reduced function in an organ, either in a quantitative or qualitative sense;
- ii) disability: the incapacity or reduced capacity to function as an individual compared with normal individuals in a population, either in a quantitative or qualitative sense; and
- iii) handicap: the sum of the deprivations and frustrations resulting from an impairment or disability, making it partly or totally impossible for an individual to fulfil a role which otherwise would have been possible (WHO Report 1980).

The WHO model has been criticised by activists of the disability movement (Oliver 1990; Abberley 1987; Finkelstein 1980) and a two-tier definition which they prefer to the three-tier one favoured by WHO has been introduced. The argument here is, that impairment refers to physical or cognitive limitations that a person may have, such as the inability to walk or speak. In contrast are the social restrictions imposed by the environment that disables one, by the discriminatory practices of society. Disabled activists argue that Society disables people with impairment, in the way it responds to their impairment (Coleridge 1995; Oliver 1988; Finkelstein 1980; Lang 1998).

Writers have written about disability and the importance of understanding the cultural relativism, or the socio-cultural phenomenon within which disability is conceptualised (Ingstad and Whyte 1996). It is societal attitudes that create the 'problem' of disability. A non-caring society disables people. The argument put forth is that it is society that should adapt to a disabled person, rather than the disabled person having to be normalised into society. The two models are known as the 'medical' and the 'social' model of disability.

The Medical Model: 'A person who is limited or prevented by an impairment from fulfilling the role that is normal for that individual' (Oliver 1990; Finkelstein 1990; also quoted in Coleridge 1995:19). Disability is a problem focussing on the individual and perceived as a deviation from the norm. The role of professionals, medical and paramedical people is to correct this problem so that the disabled person can be as normal as possible (Lang 1998:5).

The Social Model: 'A person who is restricted or prevented from participating in the mainstream of social activities by the cultural, social, physical barriers of society which takes little or no account of people who have impairments' (Oliver 1990; Finkelstein 1990 also quoted in Coleridge 1995:20).

In this thesis 'disabled children' refers to 'all children who due to impairment, disability or handicap' as stated above in the WHO classification, and adopted by GOI, 'cannot fulfil a role which otherwise would have been possible.' Since it examines policy and practice concerning 'all disabled children', the Government's definitions and classifications about each type of disability has not been relevant to include, and a broad term such as 'disabled children' is used. The term, 'children with special educational needs', or children with SEN, as disabled children are now known in the West, will not be used even when the thesis discusses areas related to the UK, Europe and the US. The term 'disabled children' understood both nationally and internationally will be used. The important development of the current disability discourse, which is the social model of disability, will also be brought into the discourse of the thesis, as it is extremely relevant. I use the term 'discourse' as a framework of discussion and an exposition of the subject.

The thesis is about disabled children under five years of age in an impoverished, socially disadvantaged area of India. Substantial research has shown the important findings of researchers, on the cognitive, social, emotional, cultural development of the child during the 0-5 years. In fact, there is now major evidence, that the optimum time for learning basic skills is those critical early years (Newell and Potts 1984; Carpenter 1994; Sylva and Lunt 1982). There is tangible evidence that children who are socially disadvantaged or disabled in some form or other suffer scholastically, linguistically and educationally (Chazan 1973; Bereiter and Engelmann 1966; Blatchford and Curtis 1981). The various strategies of intervention, in attempting to remedy these, have been compensatory education, special education and remedial education. Western countries have invested vast sums of money, researching the causation of learning difficulties, and the efficacy of various techniques (Bereiter and Engelman 1966; Woodhead 1976; Chazan and Laing 1981). Considerable research now gives credence to the value of early identification and early education for all young handicapped children (Stukat 1978; Laporta 1978; Bowley and Gardner 1980; Potts 1984; Bruininks and Lakin 1985). Widespread concern has been expressed about the plight of disabled children, who do not receive early diagnosis, education and treatment running a serious risk of acquiring secondary and tertiary handicap and lagging behind. Today, it is imperative that disabled children get services from as early an age as possible, so as to prevent secondary handicap from happening (Laporta 1978; Newell and Potts 1984; Wade and Moore 1992).

Researchers have also emphasised the paramount importance of integrating them in appropriate environments, suited to their special needs (Wedell 1982; Booth and Potts 1983; Hegarty 1993; OECD 1994). The new approach now recommends access to a common schooling for all children (Booth and Potts 1983; Bines 1986; Dessent 1987). However, integration has been possible in the industrialised countries, because the education system has evolved over a period of time, and as awareness has developed so disabled children have been mainstreamed into the normal system of education (Wedell 1982; Hegarty et al 1982; Cole 1989). Today the education of disabled children has become statutory, and Acts of Parliament passed entrusting the responsibility of providing services for handicapped people, to the State. Legislation, backed with fiscal support, in some countries, has empowered disabled children and

their families to seek legal redress, if and when they find statutory services not complying with the law or discriminating against them. Debate over segregation and mainstreaming in an ordinary school has been related to a lack of equal opportunity and a matter of human rights mandatory to a civil society.

1.2 The Indian Situation

Background

Moving on to the Indian situation, the first question that arises is, has India addressed this issue of the critical 0-5 years? This thesis examines state policy rather than private initiatives of voluntary organisations.

We find that due to other priorities and resource constraints, India has not yet succeeded in universalising primary education (Naik 1975; Aggarwal 1985; Tilak 1990). However, India has addressed the question of the pre-school years, by formulating the Integrated Child Development Scheme (or the ICDS). The programme, in keeping with the ICDS policy, is to provide health check-ups, immunisation and nutrition, referral services and informal pre-school services, for children from 0-6 years. Today the ICDS is considered to be the world's largest package of services for women and children (Sood 1987; Verma 1994; Siraj-Blatchford 1994; Swaminathan 1996). This policy and practice certainly indicates India's commitment to this important and critical period in a child's growth and development.

The second question that arises is: Has India recognised the educational vulnerability of those in the lower socio-economic groups? We find that India seems also to have done that. It has recognised the fact that children from the poorer sections of society become more deprived and acknowledged the invaluable importance of compensatory education. We find that the ICDS has been targeted for children in the weakest and most vulnerable sections of the population; for children from socially and economically disadvantaged families all over India, in the rural areas, remote tribal belts and in the peri-urban slum of the cities (GOI 1992).

The third question that arises then, is: Has India addressed the issue of disabled children as well, during the critical 0-5 year period in the impoverished vulnerable sections of the country? The practice of the ICDS by and large indicates that disabled children are not included. There are scattered pockets around the length and breadth of the country where a disabled child can be found within an ICDS-run programme. However on the whole this is not a uniform practice, and the bulk of disabled children are left out. The researcher's own work in the slums of Dharavi ⁴ for ten years indicates that disabled children are not being included in the ICDS programmes. Segregated nursery schools for different types of disability exist in Dharavi.⁵ (See Appendix 8 for two such examples).

The local administrators of the ICDS confirm that disabled children are not included. Although, the ICDS policy does not explicitly state that disabled children should not be included, the issue of disabled children is not addressed. The policy is silent on the issue.

There is enough evidence indicating that poverty and disability are closely related (Pandey and Advani 1995; Harriss-White 1995; Baquer and Sharma 1997; Coleridge 1995; Lagerwall and Tiroler 1995). A Spastics Society of India research investigation indicated that the highest incidence of disabled children is in the poorest sectors of the city, namely in the slums.⁶ Therefore, it seems that, although India recognises the critical 0-5 and the crucial needs of the socially disadvantaged child being at high risk (the ICDS takes care of the seventy per cent of the vulnerable sections of the under five population) it does not seem to address the question of the socially disadvantaged disabled child during the critical 0-5 years.

⁴ Dharavi: reputedly one of Asia's largest slums with a population of 400,000 ranging to 600,000.

⁵ The Spastics Society conducted a primary sample survey of under five population in Dharavi during 1997-98 among 3000 households; and found 3.2% disabled under-fives. Extrapolating this information to the entire slum would give us the number 609 disabled under fives in Dharavi.

⁶ Billimoria and Krishnaswamy (1986) conducted a survey for the Spastics Society of India on the 'Prevalence and Incidence of Disabled Children in Bombay'. The findings indicated that the highest incidence of disabled children was in the slums of Dharavi.

This study was planned to investigate why this has happened. Why is the ICDS not dealing with 'all needy children' as explicitly stated in the policy documents? How and when did disabled children get left out of the State programmes? Is there a conceptual confusion in understanding the term 'all needy children' or a lack of political will? How is it related to a wider socio-cultural ideological value system that has been in existence? What are the factors that could have led to the non-inclusion of disabled children?

The significance of the investigation

As far as the disabled are concerned, India's policies are similar in some ways to what was happening in Britain during the pre-Warnock years, in the mid 1960s. The disabled still remain enshrined in the ideologies of segregation, labelled and categorised according to the medical definition of their disability.

What is significant, however, is that a new direction is noticeable in India. Global initiatives for the last decade have stressed the critical importance of universalising education and of including all children, including children with disabilities. India has been a signatory to the Salamanca Declaration held in Spain on 'Education for All' in June 1994 at the World Conference on Special Needs Education. Representatives of ninety-two Governments and twenty-five international organisations signed a Declaration, which was a dynamic new statement on the education of all disabled children (UNESCO 1995).

A new legislation was enacted in 1996 known as The Persons with Disability Act which states that disabled children should, as far as possible, be educated in integrated settings. The Government of India's Education Ministry, known as the Ministry of Human Resource Development, in the Indian 8th Five Year Plan 1991-1996 had increased the budget for disabled children by more than five times (GOI 1993) for the purpose of promoting integrated education for disabled children.

A programme called the District Primary Education Programme, DPEP, was launched in 1994 by the Government, supported by the World Bank, with the aim of working out curricula, teacher training, etc. for early childhood care, including

disabled children. The most significant change proposed is that the district primary schools in the State would be held responsible for all children now, including disabled children. India was aiming to reach 'Education for All' status by the year 2000. With the establishment of the DPEP programme, no doubt India had taken a step forward in the right direction of including all disabled children as well.

What then was the explanation for the Indian Government not including disabled children within their services in the ICDS, when universal education remains a major goal? When substantial research supports pre-school programmes as a critical input for sustaining education, and when in some of the developed countries, disabled children receive services from as early an age as two?

In any country, and particularly in a country like India, where there are severe resource constraints, issues tend to remain on the level of rhetoric without being translated into reality, unless there is strong political support and ideological commitment to see them through. The question in this case is, is there a strong and clear political commitment to put policy into action? Would the Indian Government find the resources and initiate the shift in educational thinking necessary, in putting disabled children into the existing framework? What are the broader aspects of the disability discourse in India, since a major Government of India policy, such as the ICDS, continues not to include disabled children into their programmes, particularly in the late twentieth century?

This thesis argues that although current trends all over the world have moved towards the need for normalisation and equal opportunities for disabled children, and although the Government of India's 'Education For All', is a major policy, where the Government has been a signatory to a declaration on an international level, yet inclusion of disabled children is not happening in the Government's largest early childhood care programme, due to many factors. The thesis analyses the distinction between policy formulation and policy implementation, and argues that policy implementation and accountability only take place when there is strong and clear political commitment and when policy objectives have been clearly worked out. The thesis examines the framework, within which the ICDS policy and practice exist, and

argues that a lack of clear definitions, spelling out what 'all children' means, could have affected practice.

Marginalisation of people who do not fit into the norms that society creates, has drawn much attention from writers. Writers have indicated that the needs of disabled children relate to a wider system and milieu concerning the whole society and its value system (Barton and Tomlinson 1984; Fulcher 1989). We have noted that it is now strongly believed that there are social factors surrounding handicapped persons that handicap them further. Attitudes towards disability are very much dependent on the kind of society that exists, the values and beliefs that dominate, the ideological framework in which any policy gets embedded (Barton 1984; Welton and Evans 1986; Fulcher 1989). The push for integration in the Western countries has also happened, due to the wider ideological shift that has taken place in societal attitudes towards disabled children, a move that has evolved over several years from one of charity to the right to equal opportunities (Wedell 1982; Hegarty 1982; Booth and Potts 1983).

The thesis argues that another factor underpinning the marginalisation of disabled children that has taken place in India's ICDS programmes could be a socio-cultural and an ideological entrenchment, which may have contributed to their non-inclusion. The thesis moves on to a wider meta-investigation regarding the epistemological and ontological orientations of the disability discourse in India. It goes on to examine the body of knowledge that exists with regard to the historical evolution of policy for disabled children in India during the post-Independence period from 1947-1997.

The central issue examined in this thesis is the validity of a policy statement being made, without clarifying the term 'all children' to mean disabled children as well, and the milieu in which such a practice is carried out. The argument offered in the thesis is that, a policy can implicitly, although not explicitly, exclude certain beneficiaries by choosing to remain silent, non-specific, or ambivalent about their inclusion. The thesis explores this specific gap, between policy and practice, within the wider social and ideological context of the Indian situation.

1.3 The Objectives of this Study and the frame of reference

The main objective of the study was to make a critical investigation of the Government of India's policy and practice known as the Integrated Child Development Scheme administered by the Department of Women and Child within the Ministry of Human Resource Development.

The purpose of the study was to reconfirm my own experiences in Dharavi, that the ICDS had locally, as well as nationally, left out disabled children from their policy; to investigate what were the wider social and cultural implications underpinning this non-inclusion, and investigate why and how the ICDS, a policy initiative supposed to be for 'all children', had left out disabled children and their families from their agenda.

The purpose of the research was to take the disability discourse in the subcontinent incrementally further; to contribute in some small way to existing data about factors which may have contributed to the non-inclusion of disabled children from Government policy and practice; and to add, from a wider examination of the political and historical context, the socio-cultural value system, data about the overall policy for disabled children and their education in India. The thesis argued that it is in the wider framework that ICDS policy and practice may have got embedded. From the data collected, the study hoped to make some inferences about the issues and specifications that may need to be addressed, on a larger level, for inclusion of disabled children into the existing ICDS services.

The frame of reference for this study is children in the 0-6 year age group from the weakest and most vulnerable sections of Indian society. The word 'disabled children' is used to include 'all disabilities' to cover impairment, handicap or disability, as a generic term. The study does not investigate the quality of the service of the ICDS. The study investigates the policy and the action, the gap between what is stated and what is done in reality.

1.4 The Research Question

The research question is addressed in three areas: a) policy issues, the context of what, why, and how had the ICDS policy been planned; b) historical issues of the disability discourse in the Indian subcontinent; c) the social and ideological constructs within which the ICDS policy and practice exists.

(i) The Key Question

1. What was the explanation for the ICDS not explicitly excluding, but not directly addressing, the needs of the pre-school disabled child within their existing provisions for the weaker and more vulnerable sections of society?

(ii) The Subsidiary Questions

a) When was the policy made and by whom? What were the priorities? How did the issue come up on the policy agenda? How was it defined? What and how were the objectives and goals of the programme decided?

b) Who were the people behind policy-making for the disabled? What were their values, beliefs and interests?

2. What is the wider socio-cultural, political and ideological framework within which the ICDS practice exists?

a) What has been the historical evolution of social policy in India for disabled children?

b) What are people's underlying value systems with regard to disability and how are their attitudes to disability affected by their deep-rooted values?

Questions that were addressed to the community were:

3. What is the attitude of the family and the community towards their disabled child?

a) What are the factors that inhibit parents from taking their child to the local anganwadis?

b) What do they feel about their disabled child not enrolling into the anganwadi? What do they feel about their child being admitted to the anganwadi?

Questions that were addressed to the local bureaucrats were:

4. Why do the anganwadis not have any children who are disabled?

b) Why do mothers of disabled children not come for this service?

A summary of the chapters

The thesis is organised in seven parts. The first presents the research problem and the contextual background to the research question; the second presents the theoretical and conceptual background to the thesis; the third details the methodology for the investigation; the fourth reports the findings of the empirical work; the fifth provides a synthesis and analysis of the wider implications; the sixth presents a concluding discussion; the seventh presents the sources, the bibliographic references, and the appendices.

Part One: The Problem: has two chapters (Chapter 1 and 2). Chapter 1 contains definitions used in the thesis and the rationale for the research question. It presents the rationale of the critical 0-5 years, the importance and significance of these years for children from socially disadvantaged backgrounds and argues that this period is equally critical for disabled children. It moves on to the study of a Government of India policy called the ICDS, which deals with the 0-5 years, stating that its provisions are for 'all children' but in actual practice does not include disabled

children, moving on to the research question. Chapter 2 puts the research question within its context and describes the historical perspective of the educational system and the background to the ICDS as well as the demographic aspects of the research site, which is the Dharavi slum.

Part Two: The Theoretical and Conceptual Framework: Literature Review: has two chapters (Chapter 3 and 4) which is the theoretical and conceptual background to the thesis or the Literature review. Chapter 3 reviews the literature on the policy process, the factors that contribute to the formulation of policy; the politics of policy-making, the types of policy, the policy chain and the implementation chain. It presents the argument that policy-making goes through various stages in the policy formulation and policy implementation stages and argues that unless policy is clearly spelt out and all issues explicitly addressed, the implementation that follows may not be true to the policy statement. It then moves on to the literature, detailing the historical evolution of policy in India with relevance to the education and welfare of disabled children from 1947 up to 1997. Chapter 4 reviews the literature in the international scene and looks at the global initiatives that have taken place in the last three decades.

Part Three: The Findings of the Literature Review: has one chapter (Chapter 5) which analyses the findings of the literature search.

Part Four: The Methodology: has one chapter (Chapter 6) detailing the methodology for the investigation; the field study which was carried out in the slums of Dharavi in Bombay, and the semi-structured interviews with the policy makers in New Delhi. The chapter outlines the rationale for the choice of a combination of methods and examines the debate that surrounds the deductive and the inductive approaches. The range of methods used such as focus groups, triangulations through home visits and semi-structured interviews are detailed. The analysis of interviews, which generated a vast volume of data, has been done with the Nud.ist: a form of qualitative data analysis done with a computer software programme.

Part Five: The Empirical Framework: has two chapters (Chapter 7 and 8) which analyses the findings of the empirical investigation. Chapter 7 details the

findings of the study involving the community. Chapter 8 presents the policy maker's perspectives.

Part Six: The Analytical Framework: has two chapters (Chapter 9 and 10). Chapter 9 analyses the top-down (policy-maker's) bottom-up (community) investigation and concludes with a synthesis of the analyses. Chapter 10 presents a concluding discussion to the thesis.

Part Seven: Bibliography and Appendices: has three sections holding the bibliographic references, the appendices and some photographs of Dharavi, of a few children from the Spastics Society of India, from the service at Dharavi and of the researcher and a student.

2 A CONTEXTUAL BACKGROUND TO THE ICDS: AN OVERVIEW OF EDUCATION AND THE RESEARCH SITE.

Introduction

Chapter 2 puts the research question in its context. The chapter begins with a preamble, giving a broad perspective of the general educational system that has evolved, in the pre- and post- Independence period of the Indian subcontinent, setting the stage for examining the contextual background of the research question. The content of the ICDS policy and the practice is then examined, its objectives, its history, the educational structure within which the ICDS operates, the training it imparts and some of its research findings; the chapter then moves on to the research site of Dharavi, outlining some of its demographic aspects and the way ICDS functions in this slum.

2.1 India

Fifty years ago, at the 'stroke of the midnight hour' (Nehru 1947), India achieved her Independence. The first Indian Prime Minister Nehru made his famous speech to the nation and with great passion and idealism he said,

Long years ago we made a tryst with destiny, and now the time comes when we shall redeem our pledge. The achievement we celebrate today is but a step, an opening of opportunity, to the great triumphs and achievements that await us (Nehru cited in Dreze and Sen 1996:1).

He reminded the country about the challenges ahead, which included the ending of poverty, of ignorance and disease and inequality of opportunity. It is some of these ideologies that Nehru proclaimed on eradication of poverty, equality of opportunity, that this study touches upon. Fifty years after Independence, failure to achieve some of these ideals has led to a great deal of national introspection. Failure to achieve

universal education has affected certain deprived groups in the population, not least disabled children.

2.2 The scale of the problem

With a population of 950 million, India is the second most populous country in the world. Divided into 29 States, it has over 14 major languages and 316 dialects. English and Hindi (the major Indian language) have been maintained as link languages, but differences in customs, dress, religion, language and culture abound, not to mention the inequities of socio-economic levels, making India a land of contrasts and contradictions. Thirty per cent of the population lives below the poverty line and seventy percent in the rural areas.

Abysmal poverty and large income disparities are a dominant feature of the Indian polity (Dreze and Sen 1996:2).

After Independence, the pace of industrialisation increased, large and medium sized industry attracted rural masses to the towns and cities to seek employment. The urban population grew rapidly recording an average growth rate of thirty-eight per cent per annum since Independence (De Souza 1978; Singh and Pothan 1982) As a result of this urbanisation,⁷ it has been estimated that one fifth of the total population of India live in the slums or squatter settlements (De Souza 1978: xiii). An example of this is Dharavi, a shanty town in Bombay. Bombay's population today is 12.570 million (Census 1991). Half a million live in Dharavi (Jha 1995:75). As far as the number of disabled people are concerned, no accurate figures exist, but the Government of India commissioned some special surveys in 1981 and 1991 and a figure of five percent of the total population has been accepted (GOI 1991). Extrapolating this percentage to the under six population which is estimated (1971 census) at twenty per cent of the total population, the disabled under six population would be one per cent of the total population. The present population in India is estimated at 950 million. The number of under six disabled children is therefore estimated at 9.5 million.

⁷ Rural migration into the cities

2.3 Colonial Education: the inherited legacy

This section gives an overview of the historical evolution of the educational system within which the ICDS functions. Colonial education was not complementary or supplementary to indigenous educational practices, but was in fact planned as an alternative, thus replacing the indigenous system ⁸ (Naik 1975).

The broad objective of the British was to create an educational system, which would largely, be a 'pale imitation' of the English system (Naik 1975:2). In 1835, Lord Macaulay formulated the British policy of Education, which ruled the educational world of India for more than a century and even does so to some extent to the present day. Lord Macaulay rejected all that was Oriental: Indian culture, Indian languages, Literature and Indian History, and stated:

... a single shelf of a good European library was worth the whole native literature of India and Arabia ... it is, I believe, no exaggeration to say, that all the historical information which has been collected from all the books written in the Sanskrit languages is less valuable than what may be found in the most paltry abridgements used at preparatory schools in England (Macaulay 1935:349).

The idea behind education seems to have been to create a cadre of Indians who would think and express themselves like the British - a class of educated Indians who were only different in colour, but thought, spoke and conducted themselves like the British. This is reflected by Lord Macaulay's famous statement:

We want a class of persons Indian in blood and colour, but English in tastes, in opinions, in morals and in conduct (Sharp on Macaulay's Minute 1852).

⁸ Ancient forms of education in India, which was based on building up strong value systems such as strong moral character, respect for elders, helping the needy in the community, obedience etc.

Education in colonial India therefore was restricted to the upper and upper middle classes, excluding the vast majority of the masses, resulting in a split and in alienation of the masses (Naik 1975).

The multi-level education system was highly pyramidal with acute angles at the base. Primary and mass education did not receive any serious attention, as only higher education was found to be important (Tilak 1990:6).

This created a dichotomy between the elite upper class, whose sons and daughters were educated to be anglicised, and more 'British than the British' and those that could not speak the 'Queen's English', were considered to be socially of a lower level. Due to the imported model of education, this divide dominated the country. Many missionaries, charities and voluntary organisations set up schools and colleges, however the curricula had a British orientation (Naik 1975).

Education in India under the British Government was first ignored, then violently and successfully opposed, then conducted on a system now universally admitted to be erroneous, and finally placed on its present footing (Howell 1872:1).

Indigenous forms of education did continue for the broad masses, but limited by scarcity of resources, the initiatives of enlightened educational philanthropists, were only able to create small ripples. State support was limited. What was offered as State support was targeted at educational institutions teaching in the English medium and following the English curriculum.

2.4 The Post Colonial Development

When India attained Independence in 1947, she inherited the educational system prevalent during the British times. The structure and philosophy of colonial India continued to dominate the Indian educational system and determine its basic shape. Universal education remained an unfulfilled dream.

The British educational system was after all a system conceived and implemented by an alien government for a subject people. Inevitably, it had limitations. The ideal of universal education was never pushed through with the will and determination expected of a national government (GOI publication 1965:3).

The magnitude of the problems in education, which independent India had to face, can be realised partly by turning to figures for literacy and unemployment obtained at the dawn of independence in 1947. During a century of systematic state-aided educational effort, only 12.2 per cent of the people in the country had become literate.

If, together with these disappointing figures, we consider the question of quality at each stage of education, the picture becomes almost appalling. Primary schools, which were left to the care of local bodies, presented the most depressing sights; what with the poor buildings housing the schools, the academic and professional qualifications of teachers, their working conditions, the equipment, playgrounds and health-care of children. The schools were meant just to turn out ill-educated children, with a smattering of alphabet and numbers. Wastage and stagnation were rampant. Inspection, if and when it was done, was formal and mechanical. Little was done to enliven and lighten the squalor of the schools, which competed with the squalid homes from which the children came. It is only when the state of the economy, health, social status, emotional and intellectual outlook of the people enter into the calculations, one can get the true dimensions of educational problems that sought for answers at the time the British left India (GOI publication 1965:4).

After Independence in 1947, there was a massive initiative to educate the masses. India had to begin from scratch and made commendable progress during the

post-independence period. When the Planning Era ⁹ began in 1950-51, 19.2 million children were enrolled in primary schools, 4.4 million in secondary schools and 360,000 in universities and colleges of higher education (Tilak 1990).

Universal Education

According to researchers and educational analysts, while the achievements of four decades have been impressive, the failures are also shocking. The general feeling among the educational analysts is that India inherited:

A top-heavy, bottom weak, elitist
unproductive and irrelevant educational
system from the British (Naik 1975:13).

The tilt towards higher education resulted in the neglect of primary education and while India has been trying to remedy this, universal education has still not been achieved.

Of the most conspicuous failures of the Indian educational system, has been the failure in not achieving universalisation of elementary education (Tilak 1990:12). Naik (1980) writes that in spite of the constitutional directives and 'lip service paid to mass education, the progress has been agonizingly slow in the post Independence period'. This has been due to various factors such as failure to adopt the right strategy, more specifically, the large birth rate, consequent rapid growth of population which continually increased the size of the problem and the inability of Government to raise the financial resources needed to support this massive programme. Education still continues to 'benefit mainly the upper and middle classes for which it was originally designed' (Naik 1980:58).

Again, writers argue that although colonial policies of the past were responsible for some aspects of the current failures in education, India has to take the major share

⁹ The Planning Commission is a high powered Central Agency constituted in 1950 to prepare a blueprint for the development of the country. It is responsible for assessing the resources of the country and drawing up plans for the utilisation of resources.

of the blame for her State policies in the post-Independence period (Naik 1975; Tilak 1990; Aggarwal 1992; Naik 1980).

2.5 The Present Education Structure: the Ministry of Human Resource Development

Today, the Ministry of Human Resource Development (or HRD as the Ministry of Education is now called) in New Delhi, is the central body responsible for the formulation and implementation of all educational policies and programmes. The department of Women and Child Development within the HRD Ministry operates the ICDS. The Government of India has a three-tier system of governance: the central level, the state and the village or block level (or the panchayat level). The main agencies for advice in the Government of India are the Ministries (as shown in Appendix 1). The district and village level organisations are called Zilla Parishad and Gram Panchayat respectively as explained in the Glossary.

The State level

For administration every state is divided into districts. The district is further subdivided into blocks and the whole country has about 5,000 such blocks. The Department of Education headed by the Secretary (belonging to the Indian Civil Service) is responsible for the implementation of all programmes in the States. Although policy is formulated at the Centre, the States have a large degree of autonomy in the implementation.

In order to assist and advise the Ministry in the implementation of its policies and programmes, the Government has set up a number of specialised institutions at national and state levels for the development and improvement of education. Prominent among these are the National Council of Educational Research and Training (NCERT), the National Institute of Educational Planning and Management (NIEPA), the National Council for Teacher Education (NCTE), and the National Institute of Child Development and Public Co-operation (NIPCCD) (See Glossary for details about these organisations). Since the ICDS is a multi-sectoral programme, all

these agencies and organisations both at the Central and the State level are involved in different ways.

History of Early Childhood Care and Education in India

Since the ICDS is concerned with the pre-school years, it would be interesting to learn about developments of this period.

The concept of nursery education was introduced in India in the 1890s, when Scottish missionaries started the first kindergarten. In the decades before independence, early efforts included the pioneering work of Gijubhai Badheka and Tarabai Modak, pioneers who struggled to establish a number of educational institutions for young children and training centres for teachers. Maria Montessori travelled extensively round India during World War II, and her visit led to a further expansion in early child education centres. These were private initiatives, which have flourished in India. The traditional pre-school programmes in private nursery schools for the affluent, are numerous (Sood 1992; Swaminathan 1994; Verma 1994). They remain scattered and concentrated in urban settings, and confined solely to those who can afford such services (Sood 1987; Verma 1994; Swaminathan 1996).

It was only in 1953, at a national policy level, with the creation of the Central Social Welfare Board that the Government started playing a role on a broader scale. Between 1960 and 1975, several National Committees were appointed by the Government to look into child welfare activities and these recommended that a comprehensive national policy was needed to take an integrated view of the needs of children in socially disadvantaged areas (Sood 1987; Verma 1994). In 1974 the National Policy for Children declared 'children as a supremely important asset of the nation whose nurture and solicitude are the responsibility of the nation' and The National Children's Board came into existence (Sood 1987; Verma 1994). Pre-primary education is needed particularly, writes Kochar, for children of backward families, where the parents are illiterate. These schools should compensate for the unsatisfactory home environment of children from slum areas or poor families (Kochar 1981).

It was with the fifth Five Year Plan ¹⁰ (1974) that a major breakthrough was made, for the provision of early childcare by the State for children in socially disadvantaged areas with the launching of the ICDS. Beginning with 33 projects, ICDS reaches out to about 12 million children under 6 years of age and 3 million pregnant and lactating women.

The Genesis of the Integrated Child Development Scheme

The ICDS programme was a rural-based programme to improve women's literacy and nutritional growth for the child. Roy who was involved in the pilot programme writes that the primary objective was to 'bring significant decrease in infant mortality and morbidity, and an improvement in the physical, health and nutritional status of young children and pregnant and lactating mothers' (Roy et al 1981: 4). The programme was also meant to educate the rural woman through non-formal education strategies so that they could 'foster the health and well being of the family' (Roy et al 1981:4). The ICDS began with the main thrust of health for the mother and child and later the psychosocial element of pre-school activities was added. Three Ministries, the Ministry of Health and Family Planning, the Ministry of Education and Welfare (which was a combined ministry till 1964) and the Ministry of Agriculture and Community Development administer it. UNICEF and CARE (a US based NGO) were the International agencies also involved. CARE provided the nutrition component. Therefore we see that the ICDS began as an experiment of various Government of India ministries working together to develop a basic package consisting of nutrition, health and education for children and families in the poorer sectors of the country.

The Scale of the Integrated Child Development Scheme

Today, the ICDS has the largest outreach which, with planned expansion, is expected to reach fifty per cent of the vulnerable population by the end of the Eighth Plan (1994). The ICDS is considered the only countrywide programme in the world functioning on such a mammoth scale, requiring multi-sectoral operations and inter-

¹⁰ The Five-Year Plans are the mechanisms by which Government of India structured the economic development of India.

sectoral linkages for its implementation (NIPCCD 1992) and has become the world's largest attempt to provide a comprehensive package of services to the most vulnerable population of the country (Sood 1992; Saraswathi 1993; Swaminathan 1994; Verma 1994; Siraj-Blatchford 1995).

The ICDS programme marked a significant departure from the piecemeal welfare programme of the fifties and the sixties. The Government of India became committed to child development as a policy priority and has been steadily expanding the programme (Sadka UNICEF 1991). Relevant to this study, the ICDS programme is meant to be one of the tools developed to achieve universal education (Sood 1992; Saraswathi 1993; Swaminathan 1994; Verma 1994; Siraj-Blatchford 1995). Today the ICDS network consists of 3,907 projects covering nearly 70 per cent of the country's community development blocks and 260 urban slum pockets. The Centres employ nearly 500,000 paraprofessional workers. The programmes concentrate in urban slums, tribal areas, and remote rural areas. A little over fifty-seven per cent of all ICDS programmes in the country is in urban slum areas (Sood 1992; Kaul 1994; Siraj-Blatchford 1994; Swaminathan 1994; Verma, 1994).

Department of Early Childhood Care and Education (ECCE) and Department of Women and Child (WCD)

There are two departments of the Government in the Ministry of HRD, which are meant to run the programmes: the Department of Early Childhood Care and Education (ECCE) and the Department of Women and Child (WCD) who are responsible for nutrition and immunisation. However it is the Department of Women and Child that runs the ICDS programme in the country; while the ECCE is meant to play a technical role about the psycho-social development it is the WCD that is entrusted with the responsibility for the ICDS programme.

2.6 Dharavi: Site for the Research Study

This section moves on to describe Dharavi, which is reputed to be Asia's largest slum, situated in the heart of the industrial capital Bombay. It examines some of its

demographic aspects and the programme of the ICDS functioning on the ground level, relevant to the research question's frame of reference, targeting disabled pre-schoolers in a socially disadvantaged area.

Definition of Poverty

The literature abounds with various indicators and variables describing poverty, disadvantage, deprivation, and the causes and consequences of it. Slums are now found in all countries, but the definitions of poverty, poverty line, slums, vary from country to country according to socio-economic levels. According to Rutter and Madge (1976) the term 'deprivation' is the most overused term and has appeared in countless articles, books and other writings.

The term may be dismissed as mere academic disputation, not worthy of further consideration were it not for the fact that, behind the words, lie people who continue to suffer from various forms of personal and social disadvantage. The term may generate semantic confusion, but the human predicament is real enough (Rutter and Madge 1976:2).

Townsend (1979) argues that it differs from country to country, region to region.

People's needs even for food are conditioned by the society they live in and to which they belong (Townsend 1979:59).

Poverty exists when families lack the resources to obtain the types of diet or participate in activities, and have living conditions and amenities that are at variance with the society they live in. Poverty is not restricted only to the South countries in the Third World. An OECD study (1996) on 'at risk' children states that 20.4 % of children live in poverty in the US (OECD 1996).

Sen (1981) writing about poverty says that,

There is indeed much that is transparent about poverty...and one does not need to elaborate criterion or cunning

measurement or probing analysis to recognise raw poverty (Sen 1995:vii).

Definition of a slum in India

In India, the meaning of a slum is the absence of proper housing, a lack of basic amenities such as water, drainage, and sewage, an unhealthy and unhygienic environment, with high levels of pollution, a result of excessive urbanisation and population explosion (Desai and Pillai 1970; Singh and Pothan 1982; De Souza 1978; Alur 1988; Roy 1995). In India, the slum settlements are known as 'chawls, bustees, or jhopadpattis' (The glossary explains the indigenous terminology).

Dharavi is one such slum where the ICDS programme operates.

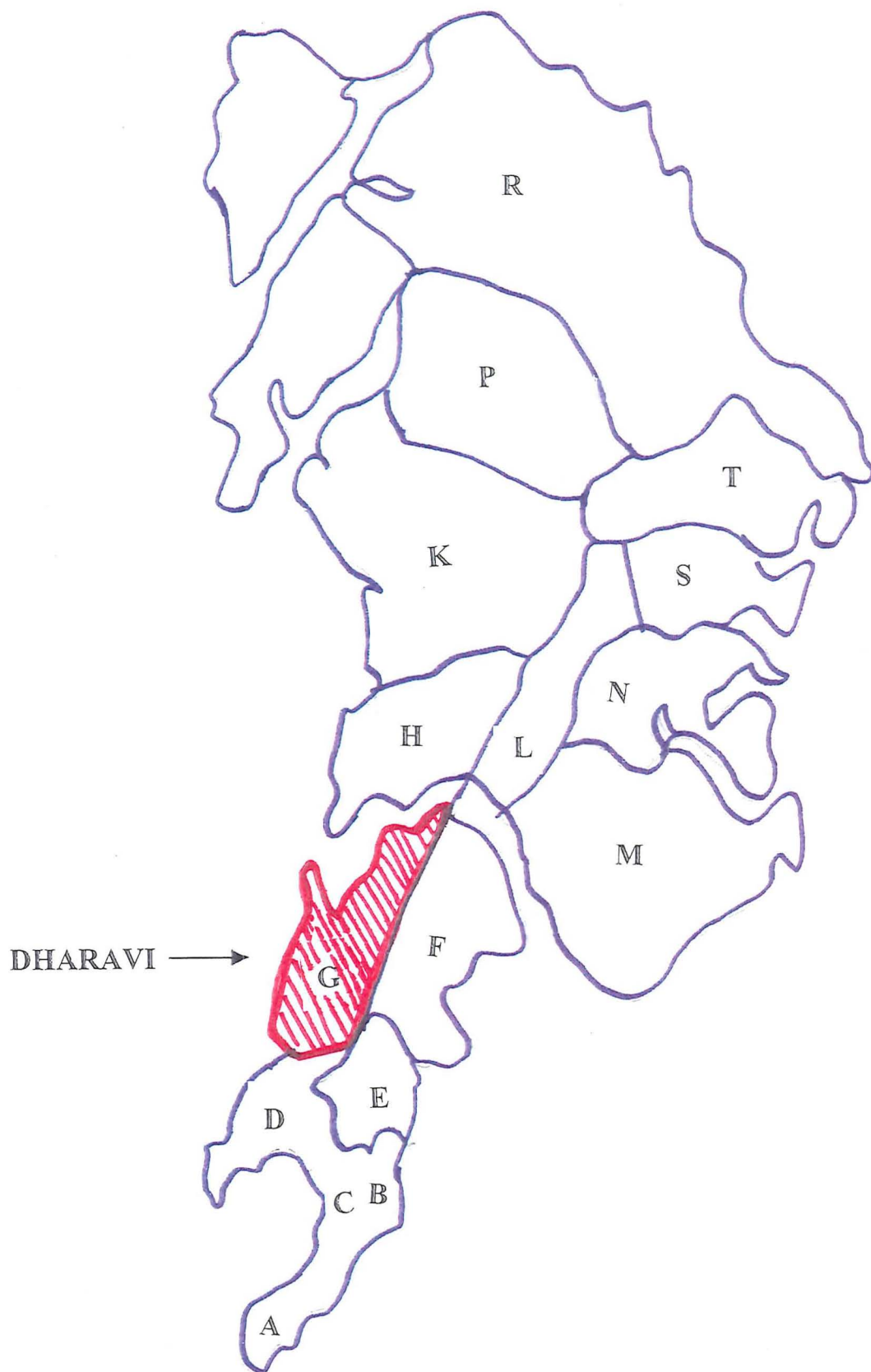
Some demographic features of Dharavi

Bombay is divided into 21 wards for administrative purposes, and Dharavi is situated in Ward G (See Map 2: Ward-wise map of Bombay overleaf). In 1986, The Spastics Society of India mounted a survey of 11,829 households, examining the prevalence and incidence of disabilities among children in the city of Bombay (Billimoria and Krishnaswamy 1986). The research revealed that 8-10 per cent of families in the sample had children with special needs, and that the majority of the children were concentrated in the G, K, and M wards where the major slums of the city, Dharavi, Khar, and Chembur are located. The Society moved into the slums and began work there. The population of Dharavi ranged between 365,000 and 400,000 (International Institute of Population Studies).

Housing

The housing in Dharavi is made up of squatter settlements, improvised shelters of pavement dwellers. The dwellings in the settlement are made of a variety of materials, and there are open drains between the closely packed huts called chawls. The typical hut is a small space of ten by ten feet, dark, windowless, with an average family of five to seven members living in it. Sanitary conditions are practically non-existent and water is scarce, available only once during the day (Alur 1988).

Map 2: Ward-wise map of Bombay



Occupations

The majority of the work force belongs to the unorganised sector, involved in unskilled or semiskilled work. They are engaged in trades such as broom-making, rag-picking, fishing, tanning and leatherwork. The women usually work as domestic servants, as maids, cooks, or sweepers or have menial factory jobs. Other forms of semi-skilled labour include plumbers, electricians, carpenters, drivers etc. Entrepreneurial skills such as leather shops, car mechanics, cafes and eateries, small shops selling consumer goods, textiles, groceries etc. abound. The average earning in Dharavi is around 2500 to 3000 rupees per month (1500 rupees being the poverty line now in India, approximately 25 pounds per month in sterling money terms).

Devoid of greenery, dusty and dirty, without any playground or park, it sprawls over 175 hectares of land (some photographs of Dharavi are included in Appendix 11). The common factors which characterise slums are present: sub-standard housing, congestion and overcrowding, lack of drainage and sewage disposal, lack of clean water facilities, low levels of health and nutrition leading to environmental deterioration and poor standards of health. Dharavi is a breeding ground for disease and pollution, with high rate of infection and disease (Alur 1988). Similar findings have been recorded in slum settings in Calcutta (Roy 1995). Dharavi would certainly fulfil the criterion of being home for some of the weaker and more vulnerable sections of the country, which is why the ICDS functions here.

2.7 The ICDS programme as found in Dharavi

The ICDS administrative offices are situated at the Local Urban Health Centre, Sion Hospital, run by the Bombay Municipal Authorities. The ICDS co-ordinates its activities from here.

The Anganwadi

The local nursery run by the ICDS is known as the 'anganwadi'. The anganwadi within the slum is the focal point for the delivery of all ICDS services. The term

‘anganwadi’ refers to a nursery school within the environment the child comes from and is supposed to be a courtyard nursery. This is more so in the rural areas. In the slums there are few courtyards and the anganwadis usually function within a small room belonging to one of the residents of the locality.

Objectives of the programme

The ICDS package provides basic services listed below to children aged 0-6 through their anganwadis, which is the same in Dharavi as it is elsewhere in the country.

- Supplementary nutrition.
- Immunisation.
- Health check-ups and referral.
- Pre-school education for children from ages 3-6.
- Health and Nutrition for Women.
- Treatment of minor illness.
- Nutrition and health education.
- Convergence of other supportive services, like water supply, sanitation, etc. (GOI 1992).

The general objectives of the programme are:

- Reduce the incidence of low birth weight and severe malnutrition among children.
- Reduce the incidence of mortality, morbidity, malnutrition, and school drop out.
- Provide the environmental conditions necessary for the mental, physical and social development of children.
- Enhance the ability of mothers to provide proper care for their children.
- Achieve effective co-ordination at the policy and implementation levels among governmental departments to promote child development



(UNICEF 1983, 1991; GOI ICDS 1992; NIPCCD 1992). Extracts from the ICDS brochure are in Appendix 2.

Type of beneficiaries

According to the Urban Health authorities functioning at Dharavi's local Hospital, records indicate that the scheme provides health check-ups to expectant and nursing mothers and other women 15-44 years; supplementary nutrition, nutrition and health education to children 0-6 years.

1. Number of under 6 children supported by ICDS in Dharavi:	19, 048
2. Number of anganwadis currently functioning:	66
3. Total population covered under ICDS:	1 69,589
4. Current estimated population of Dharavi excluding migratory population:	4 75,000
5. Total population of 0-6 years:	5 3,351
6. Total number of disabled children on the roll	14

(GOI 1998 records)

As mentioned earlier, there are some anganwadis where disabled children are to be found. NGOs have set-up nurseries for disabled children in an attempt to fill the gap. Ad hoc coverage may be taking place but it is not a uniform pattern, falling within the mandate of government policy and action. The question remained to find out why this was happening.

Restricting the coverage to children of less than six years is based on the consideration that the pre-school child is the most vulnerable and critical phase in a person's overall development when seventy-five per cent of the physical, mental and social potential is determined (GOI 1992:4).

However, out of 19,048 children (as indicated above) the number of disabled children according to hospital records is 14. The number of under five disabled children according to the extrapolation done in the Spastics Society survey of 3,000 households referred to earlier would be 609. Clearly a high proportion of disabled children are not having their needs met.

Summary

This chapter gave an overview of the pre- and post- Independence education scene and touched on the failure to achieve universal education, a significant factor that may have kept disabled children out of the purview of national services. It detailed the ICDS programme and its objectives which had been launched with a focus on nutritional growth and development of a child and lactating mother, the main objective being to decrease infant mortality and train the women from the socially disadvantaged sectors about healthcare with the component of education added later. The objectives of the ICDS had been drawn up by three Ministries and is considered the only countrywide programme in the world, functioning on such a mammoth scale, requiring multi-sectoral operations. The ICDS programme is meant to be one of the tools developed to achieve universal education. This chapter examined its functioning in the slums of Dharavi, and from the existing records it was evident that the ICDS was not addressing the issue of disabled children there.

PART TWO

THEORETICAL AND CONCEPTUAL FRAMEWORK:

A LITERATURE REVIEW

3 THE EVOLUTION OF INDIAN SOCIAL POLICY FOR THE EDUCATION OF DISABLED CHILDREN: 50 YEARS 1947-1997

Introduction

This is a review of the literature on policy and practice, on policy and special education, on the wider historical framework and the socio-cultural, political value system within which policy gets embedded. The review deals with the situation in the Indian as well as the international scene.

The formulation and the implementation of the ICDS policy cannot be understood without an examination of Indian Government policy, Chapter 3 therefore tracks the historical evolution of policy for disabled children in the Indian subcontinent from 1947 up to 1997, giving a pre- and post- overview. Chapter 4 deals with international developments, in the area of special education and policy, specifically for disabled children under five, and its implications for India. Chapter 5 deals with the findings of the review and the analysis of the literature review.

Chapter 3 consists of three sections: the first examines the historical evolution of services and the ideological and structural positions taken by the Government and the wider values allocated to the issue of education of disabled children; the second section examines the segregation and integration debate of disabled children; the third section examines the relationship between policy and practice and how this relates to the ICDS, examining core questions such as: What is meant by policy? Who makes policy? How do issues get on to the policy agenda? What are the distinctions between

policy formulation and implementation? It also examines the kind of factors that influence policy-making and the politics of policy-making. By examining the broader theoretical and conceptual framework within which policy is formulated and implemented, the aim of the literature review is to gain an insight into the situation into which Indian policy fits, and get closer to defining the gap between what is stated and what is practised in the Indian scene.

3.1 A Pre Independence overview of education for disabled children

The first organised attempts to educate disabled children were for blind children, and these were made by Christian missionaries who began by establishing schools. In 1883 at Amritsar in Punjab, Annie Sharp, an English missionary, established the first school for the blind. Interestingly enough, throughout the 19th century, an unknown number of blind children were casually integrated with sighted children, picking up whatever they could from oral repetition, which was the major tool of pedagogy. Priscilla Chapman, another missionary, remarked on a blind girl in Calcutta in 1826, who from listening to other children learned passages from the Gospel (Chapman 1839, as cited by Miles 1996:1 unpublished draft). In 1890 and 1900 Asquith and Anne Millard founded schools for blind children at Pallamkotai, Calcutta and Bombay (Kaur 1985). Since then India has witnessed a gradual development in the educational and training facilities for the blind. According to Miles (1994) there was a great deal of care in small centres across India before Independence, in which some people with disabilities did receive education and vocational training. It is reported that 'it was voluntary effort that played a pioneering role in the field of education and social service' (Gupta 1984:78).

Due to insufficient documentation, researchers over the past fifty years, both Indian and foreign are poorly informed about India's special educational needs and disability issues in the 19th century. Much inaccurate data has been copied from secondary sources which may lack reliability (Miles, 1994). According to published material regarding the pre-Independence period, Taylor and Taylor (1970) writing about the historical development of services in India, report that there was no

government action as such, concerning services for 'handicapped'¹¹ children until India became independent and that before this time, voluntary bodies had provided the only services available (Taylor and Taylor 1970).

Miles argues that:

Whereas there was no nation-wide plan to provide disability services, there were voluntary organisations taking care of the needs of disabled children, people and the Presidency Government gave financial aid, and other assistance, to institutions serving people with disability from the 19th century onwards as shown in many official records (Miles 1994:3).

Mid-Twentieth Century

The CABA Report.

In 1943, the Central Advisory Board of Education and Health (the CABA committee) appointed a joint committee to investigate into the causes of blindness and to recommend measures for the welfare of the blind. The report of the committee, submitted in 1944, became the basis of the development of services not only for the blind, but also for other groups of handicapped persons. In pursuance of one of the recommendations of this report, a small unit was created within the Ministry of Education in April 1947 to deal with the problems of the handicapped (CABA 1944).¹²

In 1944 in England, the Education Act or otherwise known as the Butler Act was passed. In the same year in India, CABA published a comprehensive report on the Post-War Educational Development of the Country, popularly known as the Sargent Report. In this report, it was recommended that provision for the handicapped was to form an essential part of the national system of education, and should be administered by the Education Department. Whenever possible, the report stated, handicapped

¹¹ The term used in the past in documents and books is 'handicapped'.

¹² The CABA report reference is shown under Sargent Report in the Bibliography.

children should not be segregated from normal children; only when the nature and extent of their defect make it necessary should they be sent to special schools (Sargent Report 1944).

The CABA Report goes on to point out that governments in India, whether central or provincial, had shown little interest in this subject and had left it almost entirely to voluntary effort. Chapter 9 of the CABA Report, represents the first official attempt to analyse the problem, estimate its extent, and suggest ways of dealing with it (Sargent Report 1944, Chapter IX CABA Report, post-war: 76-82).

According to documentation therefore, until about 1947, the then Provincial Governments had stated in various reports that the disabled child should be educated side by side with normal children. Disabled children were the responsibility of the Ministry of Education. However, no plan of action for implementation of this policy was worked out. Sporadic interest in the education and training of the handicapped was shown, usually by giving ad hoc grants to schools and other institutions for the handicapped. Missionaries from out of the country and enlightened philanthropists within the country, were the main groups of people who appear to have given attention to the question of disabled children's education in the pre-Independence period.

3.2 The Post Independence Overview

In 1947, India had around 50 schools and other establishments for the blind, while by 1965 the number had risen to 110; and about 35 schools for the deaf, which by 1965 had risen to 68. A training centre was set up in Hyderabad and a National Centre in Dehra Dun. There were no special institutions intended for the physically handicapped. It was believed that a majority of the mild physically handicapped was able to go to normal schools. There was one school for mentally retarded children in 1947. The number had risen to twenty in 1965 (GOI 1965). These instances are mentioned to indicate the adhoc efforts of NGOs in educating disabled children. During the Second Five-Year Plan (1956-61), the GOI made this pattern of services a policy and 'emphasis was laid on the development of services for the handicapped

through voluntary agencies' (GOI Planning Commission 1961:598). Although, the first Indian Education Commission or the Kothari Commission (1964-1966) recommended that,

In addition to special programmes handicapped children should be educated in normal schools, services should be developed for additional categories of children who had peculiar defects such as the partially sighted, the speech handicapped, the aphasic, the brain injured and the emotionally disturbed; the teacher training centres should be strengthened and the Ministries of Health, Education and the Social Welfare Boards, should have a co-ordinated plan for action (Kaur 1985:340).

In 1968, John Sargent reviewed the status of educational developments for disabled children and reiterated that:

Few people in these days would deny that provisions for those children who are physically or mentally handicapped should form an essential part of any national system of education (Sargent 1968:109).

Therefore, reviewing developments, 18 years after Independence, in the mid 1960s, as reported in Government of India documents, the Government's conceptualisation and ideological stand, for the education of disabled children and their education, appears to be one of contradictions. Whereas Government Commissions beginning with the Sargent Report (1944) recommend integrated education as part of State Policy, the Planning Commission during the second Five Year Plan recommended the continuance of the dependency on the voluntary sector in providing services. This led to the sustaining of the pattern of segregation (Planning Commission, GOI 1961:598).

Government Services: assistance to voluntary organisations

In 1960 this ideological confusion was intensified. The Ministry of Education, which had been responsible for the education of disabled children, was bifurcated and the Ministry of Social Welfare created. The Ministry of Social Welfare was entrusted with responsibility for the vulnerable and weaker sections of society, with rehabilitation as the main objective. The weaker sections included the scheduled caste and tribes, women and children and the disabled were put together into the Ministry of Welfare, the argument being that the weaker sections of society needed welfare and rehabilitation.

The Ministry of Social Welfare administered schemes of assistance or grants-in-aid as they are called, to voluntary organisations for providing services for disabled people. Assistance up to ninety per cent in urban, and ninety-five per cent in rural areas was given to NGOs to set up special schools and other service delivery programmes for education, training and rehabilitation of the disabled. It became established policy that, it was not the Ministry's responsibility to deliver services directly, but to give financial aid to voluntary organisations to do so.

In 1988, the Ministry of Welfare set up four premier National Institutes working in specific disability areas. The objectives were 'to develop models of care and services, conduct research, promote human resource development' (GOI 1993). 'Models of care' meant training professionals to identify disability and refer them to appropriate agencies. An Artificial Limb Manufacturing Unit was set up at Kanpur with the objectives 'of developing, manufacturing, marketing and distribution of artificial limbs' (GOI 1993). The District Rehabilitation Centres (the DRCs) were set up to provide comprehensive rehabilitation services in areas of training, employment, aids and appliances on the district levels. In the rural sector, the Council for Advancement of People's Action and Rural Technology (or Capart) was set up as part of ESCAP or the Economic and Social Commission for the Asia Pacific Region agenda (GOI 1993). The issue of education of the disabled child was not addressed.

Today however, although special schools exist for the blind, deaf, cerebral palsy, mentally handicapped and slow learners, they are run by NGOs. The Ministry of

Welfare gives some of these NGOs grants-in-aid towards operational costs. The Ministry of Welfare determines the percentage. A larger number of NGOs sustain activities through their own funding efforts and in partnership with international NGO partnerships. The present mode of service delivery is essentially within paradigms created by 'voluntary workers'¹³ and the Government. The Government's assistance in the way of grants-in-aid to voluntary organisations for the delivery of services has become the accepted policy as far as disabled children are concerned. Rehabilitation in the form of manufacturing of aids and appliances and their distribution, identification and referrals, man-power training, research and dissemination through the National Institutes are the goals for the Government. The thrust of the curriculum for manpower training or the 'promotion of human resource development' as it is described, concentrates on identification of disability and referrals (Appendix 10 details the curriculum of the National Institutes). The Government's conceptualisation of the problem remains ingrained in the belief that the education and management of disabled children needs voluntary action

Non-Government Organisations

We find therefore that voluntary agencies in India, since Independence, have provided the backbone of services in the different categories of disabilities with an impressive spread, putting disability on the map of the country (Gupta 1984; Jangira 1986). On the Indian disability scene, the group working for the blind is the oldest, and has the strongest lobby. They have been able to get for themselves maximum concessions, whereas no other disability groups have yet been able to manage this nor have the authorities thought it fit that this should be extended to others, making the policy uniform. Piecemeal responses to individual pressures have taken the place of a concerted policy. Work has been done in the areas of identification of disabilities, education, manpower training, vocational training, placement and employment. The main focus has been not so much on adulthood and employment, as on education in the early and school years. Some of the larger voluntary organisations such as the Spastics Societies, the National Association for the Blind, the National Federations

¹³ Those working for NGOs with remuneration or those working without remuneration are called voluntary workers.

for the Mentally Handicapped and the Hearing-Impaired, have produced services, which socially integrate their clients through school and higher education and employment. Some have even introduced schemes of 'arranged marriages' for their clients. Since it is not within the purview of this chapter to go into too much detail of the workings of these worthy organisations, where each one plays an excellent part on a micro level, I have only made a general statement about their contributions.

The Government's recent survey of organisations working for the disabled in the entire country (GOI 1994) indicates that there are more than 2,456 voluntary organisations in the disability area and 1,200 special schools. 450 of them receive grants from the Government towards their operational costs. The majority of voluntary organisations are autonomous (Gupta 1984; GOI 1994; Jangira 1995). The Government's approved expenditure covers thirty percent of the special schools; the remaining seventy percent of the special schools are funded privately by autonomous NGOs in the private sector. The Government spends seventy percent of their planned expenditure on the National Institutes and factories they have set up. The medical definition of disability still prevails and helps to classify the children into different groups.

Facilities for disabled children have been developed through the predominant involvement of the medical profession who chose to follow the medical model, of factors wrong within the child. This has led to the categorisation of children into handicapped and non-handicapped (Jangira 1995:10).

One of the main problems of the voluntary sector is the very limited and fast dwindling capacity to raise funds, and their increasing dependence on grants-in-aid from the Central and State Governments for survival. As they obtain a major portion of their funding from the Government, their main allegiance remains with the Government, and this weakens their position to question governmental policy. Describing the situation of receiving grants from the Government, Harriss-White (1995) reports that NGOs and State are often locked in an 'institutional embrace' and that a society relying on NGOs as the mechanism for the delivery of social welfare

‘accepts their insecurity of funding and their social costliness’ (Harriss-White 1995: 22).

Voluntary organisations can only serve on a micro level. A Government of India survey shows strong evidence of this in its report that ninety-eight per cent of disabled people in the urban and ninety-eight per cent in the rural areas are not being covered by any service at all (GOI 1994). Observing the situation on a wider level one can only infer that Government policy finds it financially convenient to allow the continuance of the special school culture set up by powerful professionals.

3.3 A General Background to the Integration/Segregation Debate in India

A review of the literature indicates that right from the first official attempts at addressing education issues in India, integrating disabled children within existing educational services as a principle was well established in policy documents. The post-war Educational Development Report states in the summary of the main conclusions that:

- (a) Provision for the mentally or physically handicapped should form an essential part of a national system of education and should be administered by the Education Department.
- (b) Hitherto in India Governments have hardly interested themselves at all in this branch of education: what has been done has been due almost entirely to voluntary effort.
- (c) Wherever possible, handicapped children should not be segregated from normal children. Only when the nature and extent of their defect make it necessary, should they be sent to special schools or institutions. Partially handicapped children should receive special treatment at ordinary schools.

(d) The blind and deaf need special educational arrangements, including specially trained teachers. It may be desirable to establish central institutions for training the teachers required.

(e) Particular care should be taken to train the handicapped, wherever possible, for remunerative employment and to find such employment for them. After-care work is essential.

(f) In the absence of any reliable data it is impossible to estimate what would be the cost of making adequate provision for the handicapped in India; 10 per cent of the total expenditure on Basic and High Schools has been set aside for special services, which include such provision, and it is hoped that this will suffice (Sargent Report 1944:82).

Following this report, a small section was set up in the Government of India to look after the needs of the handicapped.

The Kothari Commission 1964-1966

The Kothari Commission was the First Education Commission, which again brought up the issue of disabled children in the Plan of Action in 1964 (Gupta 1984; Jangira 1995) and gave strong recommendations for including disabled children into ordinary schools.

We now turn to the education of the handicapped children. Their education has to be organised not merely on humanitarian grounds of utility. Proper education generally enables a handicapped child to overcome largely his or her handicap, and makes him into a useful citizen. Social Justice also demands it. It must be remembered that the Constitutional directive on compulsory education includes handicapped children as well. Very little has been done in this field so far: and on account of several

difficulties any great improvement in the situation does not seem to be practicable in the near future. All the same, it is important that a serious beginning is made immediately.

Our proposals attempt to indicate a feasible programme of action, which may well be the foundation for a massive attack on the problem to be made in later years.

There is much in the field that we could learn from the educationally advanced countries which in recent years have developed new methods and techniques, based on advances in science and medicine (GOI 1966:123 Kothari Commission).

Elaborating on this the Commission examined the scope and size of the programme:

The primary task of education for a handicapped child is to prepare him for adjustment to a socio-cultural environment designed to meet the needs of the normal. It is essential therefore, that education of handicapped children, should be an inseparable part of the general educational system. This has several advantages of which two are important: reduction of costs and promoting mutual understanding between handicapped and non handicapped children. This has also its disadvantages. For instance many handicapped children find it psychologically disturbing to be placed in an ordinary school (GOI 1966:123 Kothari Commission).

On an overall view of the problem, however we feel that experimentation with integrated programmes is urgently required and every attempt should be made to bring in as many children in integrated programmes (GOI 1966:124 Kothari Commission).

The Commission further recommended that:

The Ministry of Education should allocate the necessary funds and NCERT should establish a cell for the study of handicapped children. The principal function of the cell would be to help in touch with the research that is being done in the country and abroad and to prepare material for teachers (GOI 1966:124 Kothari Commission).

The recommendations were endorsed in the National Policy Resolution of Parliament in 1968. Thereafter, a programme called the Integrated Education for the Disabled Scheme was begun in 1974, but placed within the Ministry of Welfare. In 1982, eight years later, this was transferred to the Ministry of HRD, and became the Department of Integrated Education (IEDC). The education of disabled children in integrated schools became the responsibility of the Ministry of Human Resources, but their education in special schools remained the responsibility of the Ministry of Welfare through the NGOs.

Project Integrated Education for the Disabled (PIED)

The National Policy on Education 1986 brought education of disabled children under the equal education opportunity provision. This envisaged education for children with mild disabilities in general schools; special schools for severely disabled; and, reorientation of teacher training programmes through inclusion of the special education component. In 1988, the Project Integrated Education Development or PIED as it was called, was launched in most states for the preparatory work of training teachers, identifying students, etc. In terms of training, the teachers received multi-category training to serve disabled children of all types. The project was a Government of India/UNICEF scheme and the UNESCO Pack (Ainscow 1994) was tested. NCERT and UNICEF launched an evaluation study. Consolidated findings, based on data gathered from PIED, were that there was increased enrolment; comparable achievement between disabled children and able-bodied children; and, remarkable retention as disabled children enrolled for the programme rarely dropped out (Mani 1994). The conclusions drawn were that the PIED experiment should not

stop with these ten blocks. The states should take it up to reach the currently unreached disabled children living in the length and breadth of India (Mani 1994). Kaur and Karanth (1993), in a critique of the PIED intervention strategies, report that it was largely focussed on children with mild to moderate disabilities that enter school without being identified as such, and eventually constitute a substantial portion of the dropouts¹⁴. The crucial aspect of the pre-school support was not dealt with adequately. According to Jangira (1995), conceptually the effort was confined to limited categories of disability, perhaps due to the magnitude of the problem. The programme came to a halt due to lack of funds and lack of initiative from the States in following it up.

The Composite Area Approach

Jangira (1995) suggested a paradigm for integration, which he called the 'Composite Area Approach', which included the pre-school disabled child. This seems to be somewhat similar to the cluster model of clustering of schools in a specified area and sharing of facilities (Lunt et al 1994). This required a range of educational provision in terms of curriculum, instructional material, instrumental aid, and of course medical, psychological and social support as required. The main goal of this model seemed to be to improve access to disabled children within the environment and neighbourhood they lived in. The paradigm envisaged optimal utilisation of existing resources. The target groups suggested were infants in the pre-school group and children ready for school. The groups were to be identified through the co-operation of the ICDS anganwadi workers, and the local health worker. These suggestions unfortunately remained on paper. The ICDS training programmes have not adopted them in their practice (Jangira 1995).

The District Primary Education Programme (or the DPEP)

The DPEP was launched in 1994 with help from international donor agencies, the World Bank being the largest donor. The main aim is to move toward universal

¹⁴ 'Drop outs and drop outism' are terms frequently used in India describing children who leave school without finishing.

education. In this programme a very large component has been added for integration of mild to moderate disabled children. The objectives are to encourage integration in the areas of teacher training, to remove architectural barriers and to provide aids. With the beginning of the DPEP, India has taken a step forward towards integration of disabled children (Pandey 1995).

Aggarwal reviewing current developments in education writes that 28,000 children spread over 6,000 schools are presently receiving benefits under the integration scheme. A much larger number are receiving indirect benefit through special teachers and other learning materials (Aggarwal 1992). According to Miles (1985) and Dasgupta (1997 unpublished draft), the number of disabled children in ordinary schools far exceeds the number of disabled children in special schools. The fact that there are States which do not have any special schools has no doubt helped 'casual integration' to take place (Miles 1985).

3.4 Legislation

In India, poverty, caste and gender push disability to the lowest of priorities (Harriss-White 1995). Within the ambit of the overall perspective, the Constitution of India has attempted to focus on the needs of persons with disabilities in Article 41. This Article is part of the Constituent Assembly's attempt to direct the State's effort in areas which are considered desirable but which cannot be enforced.

Article 41 reads 'The State shall within the limits of its economic development make effective provision for securing the rights to work, to education and to public assistance in cases of unemployment, old age, sickness, disablement and in other cases of undesired want'. Article 41, is the only article explicitly to mention disabled people. The Constitution of India (adopted on January 26, 1951) in Article 45 directs State Policy as follows:

Free and compulsory education should be provided for all children until they complete the age of 14 (Constitution of India 1951 Article 45).

It is here where perhaps what ‘all children’ mean should perhaps have been elucidated. The deprived scheduled castes and the scheduled tribes who have historically had a strong politically lobby, begun by the forefathers of the nation such as Mahatma Gandhi and Dr.Ambedkar, have a clause within the Constitution, defining and establishing their entitlements. Article 46, declares that *‘the State shall promote with special care the education of the weaker sections, in particular of the Scheduled caste and the Scheduled Tribes’* (Article 46 Constitution of India).

Regarding disabled children, Article 41 of the Constitution, on the other hand, envisages that the State *shall within the limits of its economic capacity and development* make effective provision securing the right to work, old age, sickness and disablement. The words *‘limits of its economic capacity and development’* for provisions related to ‘disablement’ seems to contradict the inclusiveness suggested in Article 45; nor does it have the specificity of a mandate as we see in Article 46, regarding the scheduled caste.

Another lacuna, we note, is that the framers of the Constitution did not make free and compulsory education a fundamental right, but merely a directive principle to guide the direction of state policy. With such provision, the individual is not empowered to seek legal redress against the state. State intervention in this area has therefore remained a matter of discretion rather than an agenda for immediate action. State intervention in special education is an outcome that has sprung from the legislative and constitutional directives to universalise elementary education (Naik 1984; Aggarwal 1992; Jangira 1995).

Venkatesh (1995), a disabled activist, argues that

Political manifestos of the last 45 years in India have not included disability as an issue. The scattered disabled population does not have political clout, as it is not organised to campaign for its rights (ADD India 1995).

The 1994 Persons with Disability Act

A recent landmark in the history of evolution of services has been the Persons With Disability Act which was enacted in 1994 in pursuance of India being a signatory to ESCAP (the Economic and Social Commission for the Asia Pacific) which had adopted a Proclamation on the Full Participation and Equality of People with Disabilities in the Asia Pacific Region. The Act covers integrated education, vocational training, employment, and housing and even leisure activities. The Act is utopian, covering all areas of life, but comes with no fiscal support and no enforcement agency to ensure compliance. Although India now has legislation protecting the rights of disabled people, initiatives to promote legislative provisions for persons with disabilities suffer from what Alston (1994) describes,

Rights without mechanisms to claim and
without obligation to provide are empty
(Cited in Harriss-White 1995:21).

3.5 The Present Scenario 1997

The Ministry of Welfare¹⁵ remains the nodal Ministry for the welfare of disabled children. The Ministry of Welfare deals with the special school sector whereas the Ministry of HRD is dealing with integration. This has led to the ambiguous situation of two ministries targeting the same group, but with two separate agendas. The special school professionals retain their vested interests in maintaining their institutions, funded by the Ministry of Welfare. The ordinary schools who admit disabled children obtain funding from the Ministry of Human Resources under their integration scheme. Not many attempts have been made to move special schools towards integration nor have many debates been generated on the issue, an example of what has been termed ‘dualism’ of government policy (Welton and Evans 1986:217).

This review of the Indian situation indicates that there is interest in the area of integration. In pursuance of the Directive Principles of State Policy set out in the Constitution, various Education Commissions and International Agency

¹⁵ Now called the Ministry for Social Justice and Empowerment.

recommendations, various schemes have been launched by the government through PIED in the past and DPEP in the present to promote inclusion in ordinary schools. However, as Dasgupta (1997) ¹⁶ reports,

India has witnessed a phenomenal expansion of educational opportunities in the post- Independence period. However disabled children have not benefited substantially from this growth in educational facilities (Dasgupta 1997:1 unpublished draft).

3.6 The Integrated Child Development Scheme: the structure

At the Central level, the Department of Women and Child Development, within the Ministry of Human Resource Development, is the nodal department for the implementation of the ICDS. The ICDS spans several ministries and departments. There are two departments that are intrinsically involved in administering the ICDS, the Department of Early Childhood Care (ECCE) and the Department of Women and Child Development (WCD). The Department of Early Childhood Care is supposed to monitor the psychosocial and cognitive element of the programme and runs other early childhood programmes, having a technical role to play. The main responsibility for the ICDS, is with the Department of Women and Child, which has a larger budget than ECCE. There are two Secretaries; one in charge of education, under whom the ECCE functions, and one in charge of women and child development, under whom WCD functions. The ministries involved with the ICDS are several; the Ministries of Health, Agriculture and Community Development, Rural and Tribal Development and Education and Welfare. Since this is a huge programme and a multi-departmental and inter-sectoral one, the co-ordination machinery has been set up at all levels of management. There is a long line of bureaucrats. The Chief Development Project Officer, (known as the CDPO) and the Medical Officer (or the MO) under supervision of district authorities co-ordinates the ICDS implementation at the village level. The Deputy Commissioner or Collector is responsible for co-ordinating the

¹⁶ P. R. Dasgupta is the Education Secretary of the Ministry of HRD. He initiated the first major debate on integration through a series of conferences in 1997 together with the Spastics Society of India.

implementation of the scheme at the district level. Districts having five or more ICDS Projects have ICDS monitoring cells. These include a Programme Officer, a statistical assistant, an office supervisor, an upper division clerk. Districts with eighty percent coverage have a nutritionist, a pre-school instructor, a social work instructor, a health education instructor, an accountant, and a typist. ICDS cells have been set up at the state headquarters to monitor the programme at the state level. At the state level, the secretary (a civil servant) designated by the state government is responsible for the implementation of the programme (ICDS: CTC 1995).

The ICDS network consists of 3,907 projects, covering nearly seventy percent of the country's community development blocks and 260 urban slum pockets. Several aid agencies are involved with the ICDS. The World Food programme and Care, an American agency, provide sixty percent of the supplementary food to the ICDS. The main objective of the ICDS is to provide a package of supplementary nutrition, immunisation, health education, family planning and the provision of safe drinking water. The target group to receive this is nursing and pregnant mothers and children in the age group of 0-6 years. In 1975, the Indian Association for Pre-school education pushed through a proposal, suggesting that ICDS should broaden its services to include a psychosocial component, and in 1975, an additional component of non-formal early education for pre-school children began (GOI ICDS 1992; Verma 1994; Siraj-Blatchford 1995). The ICDS is fully funded by the Central Government, State Governments only administer the programme. The Women's group, a political strong group, is the group behind the ICDS, and has a strong influence on policy and practice.

Training

An anganwadi worker (AWW) runs each anganwadi. The Anganwadi Worker is the main person that the mother and child deals with in the field. She is the key worker and the first paraprofessional in the service. The course trains women from the local community with minimal educational qualifications (Sood 1992; NIPCCD 1989; Swaminathan 1994).

There are 300 Anganwadi Worker Training Institutions or Centres conducted by the Indian Council for Child Welfare. The National Institute of Public Co-operation (NIPCCD) is responsible for the curriculum and the training. ICDS has been criticised for the lack of quality in their pre-school anganwadi programmes. At present the courses are tightly structured and leave little room for flexibility. The course is heavily orientated toward health and nutrition (Punhani and Mahajan 1985; Sood 1992; Siraj-Blatchford 1994; Verma 1994). Siraj-Blatchford (1994) reports that the local authorities and ICDS functionaries have expressed concern about their training, as little time is devoted in teaching them about the cognitive, social and emotional development of the child, nor are they equipped with the skills to cope with the field situation (Siraj-Blatchford 1994). Swaminathan (1994) writes that,

...the anganwadi workers must devote enormous amount of time to learning record-keeping and administrative procedures which takes up so much of their training time. Therefore, it is not surprising that the anganwadi worker does not fully acquire the necessary skills to perform her varied tasks (Swaminathan 1994:71).

Because of the limited period of training most anganwadi workers resort to more formal methods of teaching in the anganwadis.

More emphasis on organisation, space and time management could help anganwadi workers to break the mould of having young children seated in rows learning passively (Siraj-Blatchford 1994:63).

Siraj-Blatchford (1995) goes on to argue that,

Scrutiny of the documentation, field observations and lengthy discussions with workers at all levels lead to the conclusion, however, that ICDS is integrated in concept and at a policy level, but not in practice (Siraj-Blatchford UNESCO 1995).

She goes on to report that due to a 'vertical structure of services, an uneven distribution of power among those charged with implementing the project, there is a lack of effective co-ordination at policy and implementation levels' (Siraj Blatchford 1995:10). To return to the research question being investigated, the issue is why the ICDS practice does not include the disabled child when the policy directs 'all children' to be included. This brings us to the question, which the next section examines, of what is meant by 'policy' and what is the distinction between 'policy' and 'practice'.

3.7 In Terms of a Policy Discourse: the relationship between policy and practice

Defining Policy

The term 'policy' is widely used and has been defined in various ways. Hill (1993) writes that 'policy' means defining objectives, setting priorities, describing the plan of action and specifying rules. Hogwood and Gunn (1984) suggest, that 'policy' can be used as a label for a field of governmental activity which can cover past, current and potential activities, although making no distinction between 'policy as aspiration and policy as achievement nor making a distinction between policy as action and policy as inaction' (Hogwood and Gunn 1984:13). The phrase a 'field of government activity' makes specific references to government's policy that could be about industry, health or education, a broad label which includes all areas that government, may be involved with. 'Policy' can also be used to mean 'a programme' referring to a specified government activity involving a particular package of provisions, organisation, and resources. One can therefore refer to a school-meals programme or a subsidised housing programme, or in this case the ICDS programme. 'Programmes' are seen as a way for governments to pursue their broader objectives (Hogwood and Gunn 1984). 'Policies' are contingent in the sense that they refer to and depend upon 'a specified situation' (Hill 1993). 'Policy' can be seen as an 'output' or what governments usually deliver, compared to what they have promised to deliver. Colebatch (1998) describes policy as a concept to make sense of public life and the way we are governed (Colebatch 1998). Walt (1994) suggests that the reason why we are concerned with the formal institutions of government is that they provide the structure within which

the public policy takes place. Writers agree, that anything meriting the title of 'policy' 'must contain some element of purposiveness' (Hogwood and Gunn 1984:22) and that policy is synonymous with decision-making (Hogwood and Gunn 1984; Hill 1990; Walt 1994).

Policy should involve more than intention or statement of intent...it should represent what governments actually do (Walt 1994:41).

Walt (1994) argues, that policy, 'must include what Governments say they will do, what they actually do, and what they decide not to do' (Walt 1994:41). Policy is about what 'governments choose to do and what they choose not to do' (Dye 1984:3). Heclo (1972) suggests, 'a policy can consist of what is not being done' (cited in Hogwood and Gunn 1984:21).

The term policy needs to embrace both what is intended and what occurs as a result of the intention; any use which excluded unintended results...would surely be impoverished (Heclo 1972 cited by Hogwood and Gunn 1984:22).

Policy can also be 'failure to act or deliberate decisions not to act' (Hogwood and Gunn 1984:20). However, Hogwood and Gunn (1984) argue, that 'policy as inaction is much more difficult to pin down and analyse than policy in action' (Hogwood and Gunn 1984:21). Policy as a 'process' involves a policy developing over a length of time, an approach that has been called the 'processual approach' referring to the study of the various stages that policy goes through (Hogwood and Gunn 1984:24). Bachrach and Baratz (1977) argue for a fresh approach to the study of policy, which recognises the existence of decisions as well as 'non-decisions' (Bachrach and Baratz 1977:16).

It has been written that the definition of policy is subjective, because we all have our own 'conceptual lens' (Allison 1971) through which we view policy. There is no single clear meaning. It is also issue-based within a context (Hogwood and Gunn 1984; Hill 1993; Walt 1994). In developing a terminology for this thesis, the term 'policy' will be used to refer to a government activity, or a 'programme,' with its

objectives, resources, and organisation; the ICDS policy or programme being a government activity, with its objectives, organisation and resource allocation. In analysing the government's programme, the investigation will include the study of the policy process, policy in action as well as policy inaction, what the government proposes to do, and what it actually does in real life, decision-making, as well as non decision-making, and why certain issues are not included in the agenda of policy-making.

Defining Policy-making

Moving on to policy-making, people involved in the process of policy-making and government are a wide range of people from 'differing concerns and varying relationships with each other'. Colebatch suggests that any decision on policy rests on three key assumptions, which are coherence, hierarchy and instrumentality (Colebatch 1998). *Coherence* becomes a central problem, one of getting all the different elements to focus on the same question with a degree of coherence or harmony. Colebatch (1998), argues that policy-making looks less like 'a single minded exercise of choice and more like a pattern of interaction between different participants, a process of 'pulling and hauling in which the different players try to shape activity in ways which reflect their particular perspective' (Colebatch 1998:4). *Hierarchy*, Colebatch (1998) describes as instructions being given from the 'top' in the policy process. Policy is seen as a course of action endorsed by 'the government', the 'authorities', or the 'state'. It is seen as 'an authoritative determination' of what will be done in a certain area, decided by government, as clearly the different groups will go in different ways. Therefore, Colebatch (1998) describes government endorsement of a course of action as a line of authority, a 'central nervous system' of authority in the policy process that determines a line of action. The third assumption he terms *Instrumentality* and this, he argues, is about setting goals and solving problems. Policy is in pursuit of certain purpose ('policy objectives'); these can be broadly or specifically stated or less clearly stated, 'but policy is to be understood as problems and solutions' (Colebatch 1998:4). The purpose of the ICDS programmes, its objectives, the 'authorities' who endorsed the policy, the problems it was supposed to solve are all issues important to consider.

Policies are not made in a vacuum but reveal 'a world view' or the 'value system' of those in power. Easton describes public policy (1957) 'as an authoritative allocation of values' in his systems based theory. According to Easton (1957) a way to conceive of policy is to think of it as a response to a political system, to forces brought to bear upon it from the environment. Forces generated from the environment are known as *inputs*. The *environment* is any condition defined as external to the boundaries of the political system. The *political system* is a group of interrelated structures and processes, which functions authoritatively to allocate values for a society. *Outputs* are the value allocations of the system (Easton 1957 cited by Dye 1984:40). Easton's 'system approach' stresses the responses of the whole political system to demands made on it from the environment and how policies are fed back to the political system to ensure that consensus is maintained (Dye 1984; Walt 1994). The activities of groups and individuals within a political system are heavily influenced by the nature of the environment.

Environmental conditions and resources greatly influence the character of the political system and the content of a policy (Dye 1984:318).

Dye (1984) argues that 'it cannot be expected that policies are made at variance with environmental resources and constraints' (Dye 1984:318). The study of the environmental pressures and constraints in a country like India and the factors that influence the thinking in the Indian polity would be important to examine.

Policy analysis can be descriptive and prescriptive. Descriptive policy analysis is concerned with *how policies are made* as an academic exercise, concerned with advancing understanding. Prescriptive policy analysis is concerned with *how policies should be made* a practical exercise, concerned with effectiveness. In both activities, policy analysis is not neutral. It is concerned with the values contributing to the solution of social problems. This study is a 'policy study', with a systems approach. It is essentially descriptive and explanatory rather than prescriptive, studying the environment and the social system in which policy is embedded. The study aims to go backwards to create the events and analyse the reasons for the non-inclusion of disabled children in the ICDS programme. Elmore (1980) uses a term known as

‘backward mapping’ which he defines as ‘backward reasoning’ from the hub of the problem which the policy is addressed, to the rules, procedures and structures, which have a close proximity to the policy instruments that are supposed to make feasible the policy objectives (Elmore 1980:1). Having worked in the field and observed the non-inclusion of disabled children, I now intend to go backwards in mapping the environment, the social structure, the conceptual schema and studying the actions of the state, as an overriding authority in the development of policy for the disabled. The study of policy content, the origin, the intent, and operation of the ICDS policy and the contextual milieu in which policy was designed, therefore, seem important issues to examine.

The stages of the policy-making process

The most common framework describing the policy-making stages, goes from problem identification to policy evaluation. Most attempts to depict the phases, include some of the stages, although they are not supposed to be definitive, and different stages of policy making are described differently.

Walt (1994) describes it in four stages.

1. Problem Identification and Issue recognition. How do issues get on to the policy agenda? Why do some issues not even get discussed?
2. Policy Formulation. Who formulates policy?
3. Policy Implementation. Arguably the most important aspect of policy... yet often gets short shrift. What resources are there? Who should be involved? How can implementation be enforced?
4. Policy Evaluation. What happens once a policy is put into effect? Is it monitored? Does it achieve its objectives? Does it have unintended consequences? (Walt 1994:45).

Kingdon (1984) describes them as a set of processes that include at least:

1. The setting of the agenda.
2. The specification of alternatives from which a choice is made.
3. An authoritative choice among those specified alternatives.
4. The implementation of the decision.

(Kingdon 1984:3).

Hogwood and Gunn's (1984) typology provides a process of nine stages:

1. Deciding to decide (issue search or agenda setting).
2. Deciding how to decide (or issue filtration).
3. Issue definition.
4. Forecasting.
5. Setting objectives and priorities.
6. Option analysis.
7. Policy implementation, monitoring and control.
8. Evaluation and review.
9. Policy maintenance, succession or termination.

(Hogwood and Gunn 1984:24).

Dye (1984) describes it as a series of political activities involving, problem identification, formulation, legitimisation, implementation and evaluation. The policy process therefore follows a certain set of patterns or activities.

Critique of the model of the policy process.

The above outlined stages suggest policy as a linear process through sequential phases taking place in a rational manner. This clearly is not what happens. Arguing for issue definition which should take place in the early stages could be a highly political

rather than a technical activity shaping all the stages of analysis (Hogwood and Gunn 1984). Walt 1994 argues that there is an invisible line between stages 2 and 3. The stages do not proceed in a sequential manner and sometimes the dividing line between the various activities is blurred. For example it may be only in the stage of implementation that questions are raised about the objectives of the programme. A lesson often learnt at the evaluation stage is that the prior activity of actually defining the problem to which the programme is addressed has never been understood, or perhaps that a consensus was assumed which did not exist.

3.8 Policy formulation Stage: deciding to decide or issue identification

How are certain issues identified? How are certain issues taken on board and others ignored? Hogwood and Gunn (1984) write about the identification and anticipation of a problem as the first important stage in the policy process.

The potential contributions which analysis can make at later stages of the policy process depend on when and how a potential public policy or problem is initially identified (Hogwood and Gunn 1984:68).

Who sets the agenda? Walt (1994) argues that government clearly decides what policies need changing, revising or introducing. Governments pursue an active programme of issue search, as they anticipate problems, and their ramifications before a problem or crisis occurs, and a failure to identify issues at an early stage means that many issues can be foreclosed because of time constraints or resource. There are various agenda setters such as party leaders, interest groups, influential senior officials, and advisers. Media or the 'gatekeepers' of the mass media, play a critical role. Certain areas such as ecology or the environment have been well served (Hogwood and Gunn 1984).

Elite preferences are more likely to be in accord with public policy than mass preferences. This finding is well supported in the existing literature (Dye 1984:322).

At this policy formulation stage a list of problems is identified narrowing down to focus on issues. The question is how is the list of problems selected that are to be addressed?

Deciding what will be the 'problem' is clearly far more important than deciding what will be the solution (Dye 1984:325).

Once the problem has been identified it requires definition. The issue definition stage is crucial in shaping the remaining stages of the political process. Quite often it is difficult to come out with an 'unambiguous definition' and often a convenient formulation of the issue is adopted without the matter having been given enough thought (Hogwood and Gunn 1984).

Non decision-making

Bachrach and Baratz (1977) argue that policy choices are often made in the absence of a clear-cut decision and that political systems and subsystems develop a 'mobilisation of bias' (Schattschneider 1960:71),

... a set of predominant values, beliefs, rituals and institutional procedures (rules of the game) that operate systematically and consistently to the benefit of certain persons and groups at the expense of others (Bachrach and Baratz 1977:43).

According to them 'a primary method for sustaining a given mobilisation of bias is non-decision making' (Bachrach and Baratz 1977:46). Non-decision making can take several forms:

Demands for change in the existing allocation of benefits and privileges can be suffocated, can be kept covert, killed before they gain access to the relevant decision making committee, or maimed or destroyed in the implementation stage (Bachrach and Baratz 1977:44).

Non-decision making can be a subtle process when issues remain latent, and fail to enter the policy agenda. Policy issues do not come on to the policy agenda for discussion. This may be because policymakers are not aware of the issues or have decided for a number of reasons not to act. They may be against the interests of those in power (Walt 1994:60). Potential issues are kept off the agenda by either action or inaction (Lukes 1974). Most theorists would agree that the ability of citizens to get issues on to the agenda of decision-makers is not evenly distributed and that some do not have access to the decision-makers (Hogwood and Gunn 1984; Bachrach and Baratz 1977; Lukes 1974; Walt 1994).

Conditions in society which are not defined as a problem and for which alternatives are never proposed, never become policy issues.

Government does nothing and conditions remain the same (Dye 1984:325).

Non decision-making may occur when dominant groups, also referred to as 'elite groups' (Bachrach and Baratz 1977; Dye 1984; Walt 1994) 'act openly or covertly to suppress an issue' (Bachrach and Baratz 1977; Dye 1984) for reasons of feeling threatened. Non decision-making can also occur when administrative officials or bureaucrats anticipate that elites will not favour a particular idea and they do not want to 'rock the boat' and so they drop the idea (Dye 1984:327).

Some groups are so powerless that their demands cannot get on to the political agenda. Lukes (1974) goes even further and suggests that some sections of society are so lacking in power that they cannot even mobilize and articulate their demands. Again that people can 'consciously or unconsciously create barriers or reinforce barriers' (Bachrach and Baratz 1977) and according to Schattschneider (1960) all political organisations have a bias 'in favour of the exploitation of some kinds of conflict and the suppression of others' and this he terms as the 'mobilisation of bias' (Schattschneider 1960:71).

Finally, non decision-making may occur because the political system is itself structured in such a way that it facilitates the resolution of some issues and blocks

others, a 'mobilisation of bias' within the political system itself. (Schattschneider 1960:31).

Some relevance can be found in the group of people in this study who tend to be 'powerless' and socially disadvantaged; concepts of 'mobilisation of bias' within institutions, 'non decision making' amongst the policy-makers are critical issues for the study of the ICDS policy formulation, which will need examining.

Policy implementation stage

The interaction between policy making and policy implementation has a thin dividing line (Hogwood and Gunn 1984; Hill 1993; Walt 1994; Colebatch 1998). For effective policy implementation, it is crucial that the policy problems are considered in advance of the implementation. Implementation involves a process of interaction with members who may have different values and priorities. Hogwood and Gunn (1984) argue that to understand policy failure one should distinguish between *non-implementation* and *implementation*. It is not just identification of goals but that the goals have to be put into practice. The outcome has to match the stated objectives (Colebatch 1998). However policy implementation cannot take place without formulation happening.

3.9 The relationship between policy and practice and the ICDS

Policy formulation and policy implementation

Policy-making is about formulation and choosing objectives, as well as implementation and accomplishing objectives. Policy formulation and policy implementation are not two distinct processes. 'There is no clear cut off point when policy making stops and implementation begins' (Goacher et al 1988:72). The 'policy implementation chain' (Hill 1980) has been described as a flow of activities involving a process of interaction with people who may have different values and priorities. Whitmore (1984) has described the stage of policy formulation and policy implementation as a multidimensional model, comparing it to the layers of an onion

and describing it as a complex and interactive flow of activities between policy-makers and implementations. Barrett and Fudge (1981) writing about policy and action suggest that it needs to be regarded as a process of interaction and negotiation, taking place over time, between those seeking to put policy into effect and those upon whom action depends (Barrett and Fudge 1981:207).

Issue definition and setting objectives during the ICDS policy-making process.

Policies embody a theory of cause and effect, of problems and solution. When the policy-maker's intentions are carried out the desired objectives have been achieved (Hogwood and Gunn 1984; Hill 1993; Walt 1994; Colebatch 1998). Often there is a mismatch between what is the declared statement of intent and what is the ground reality. The study of the policy process showed that issue identification is a crucial activity before decision-making takes place. Issue identification and what gets on the policy making agenda are activities that precede decision-making. Therefore, for a policy to become operational, the definition of the problem clearly becomes a priority. However, policy issues can only be defined if certain conditions in society have been identified and brought to the attention of the policy-makers. Therefore, issues need to get on to the political agenda. Dye (1984) argues that policies do not just happen.

Creating an issue, dramatising it, calling attention to it and pressurising government to do something about it are important political tactics (Dye 1984:326).

The purpose, as Dye suggests 'is to lay the groundwork for making policy into law' (Dye 1984:331). Colebatch (1998) suggests that some would argue that having 'a formal decision is only the beginning of the policy process and the critical thing is what happens as a consequence' (Colebatch 1998:9). The question of resource allocation, the question of staff training and staff allocation comes in.

For this reason policy has to be understood not in terms of intent, but of commitment (Colebatch 1998:9).

Observing the practice and the non-inclusion of the disabled child in the ICDS programme, and bearing in mind the linkage between policy formulation and

implementation, the areas of issue identification, issue definition, how the objectives for the ICDS programme was formulated, are crucial issues to investigate.

Street level bureaucrats

Lipsky (1980) uses the term 'street level bureaucrats' to describe those workers, who directly interact with the people on the ground level and administer the policy. The ICDS is an over-elaborate structure, with hierarchical bureaucratic control. While investigating the ICDS policy, Lipsky's (1980) theory of 'street level bureaucracy' appears to be relevant to policy implementation on the ground level. The essence of Lipsky's theory is that the 'street level bureaucrat' in charge of dispensing the services has a huge amount of discretionary power and considerable autonomy. This power is 'accompanied with the dilemma of working at the sharp end of resource allocation in a situation where demands far exceed supply' (Hudson 1993). Lipsky's power refers not so much to the dilemma as to the considerable amount of discretion. Hudson (1993) argues 'if necessary, street level bureaucrats can simply control clients or at least obtain their co-operation with client processing procedures' (Hudson 1993:388). Lipsky himself argues that accountability to the organisation is virtually impossible to achieve where street level bureaucrats exercise a high degree of discretion.

In the ICDS, the street level bureaucrats are the anganwadi workers and the supervisors; over them are the CDPOs and the MOs. The nurseries or anganwadis are the venues where the actual delivery of services takes place. The nutritional meal is prepared here by the helper to the anganwadis. The supervisors monitor the child's growth. The Government supplies free meals. If policy is not clear about the kind of clients that this is meant for, and if the specification of what 'all children' means is unclear, the street level bureaucrat will have the discretion and control to decide who the client should be. Weatherley and Lipsky (1977) investigating 'street level bureaucrats' and their response to the special-educational law called Chapter 766 in a school in Massachusetts found that ultimately policy is made real by the action of *individual workers on the street level*. In the Massachusetts research project the 'street level' workers together with local administrators made decisions about the way

in which disabled children's special needs were to be defined and met. The findings showed that street level bureaucracy with its highly discretionary powers, routinised matters, rationed services, and tended to modify goals. Weatherley and Lipsky (1977) argue that the lowest levels of the policy chain can become makers of policy and that

... the relationship between policy formulation and implementation is a problematic one and in a sense the meaning of policy cannot be known unless it is worked out in practice at the street level (Weatherley and Lipsky 1977:178).

This was a sober lesson of how difficult it is to integrate services for a stigmatised group and how important and critical the role of law or policy was in legitimising new conceptions (Weatherley and Lipsky 1977:197).

Law affects the work situation of those at the local level ultimately responsible for the implementation of a policy (Weatherley and Lipsky 1977). 'The role of law' and the 'policy legitimating practice' become a dominant discourse in the examination of the ICDS. The anganwadi workers and supervisors are the street level workers who are the implementers and dispensers of policy, could be described as 'gatekeepers to relatively powerless groups' (Vincent, et al 1996: 481).

Political and social systems tend to build up a set of values and procedures which favour certain groups, more powerful and influential than others, and invariably the policy outputs of the system allocate more values and benefits to one group over the other (Bachrach and Baratz 1970; Lukes 1974; Dye 1984). The street level bureaucracy conducting the ICDS programme at Dharavi is dealing with a relatively powerless group where the needs of some members of the group have not been legitimised. 'In what way does street level bureaucracy reflect and perpetuate the values of a larger society?' (Hudson 1993:396). Writers have argued that a wider value system underlies policy discourses. The values of society are reflected in the broader socio-cultural, ideological and political framework of society (Bachrach and Baratz 1970; Barton and Tomlinson 1984; Hudson 1993). In the Indian context too, consideration of the socio-economic, cultural conditions, the political climate, the

values placed on issues concerning gender, caste, class, the overall educational system, issues which form a bedrock on which a general policy of inclusion of disabled children into existing services is embedded, will be important to investigate in understanding the non inclusion being carried out by street level bureaucrats in the practice of the ICDS policy.

Summary

Concluding the chapter on the first part of the literature review about the Indian situation, one can say that research indicates that State policy does exist for integrating disabled children in India. The concept of integration appears to remain scattered, unconnected and isolated, without having been implemented in an organised coherent manner aiming at the broad mass of disabled children.

Reviewing the stages of how policy gets formulated and implemented, we come to understand that policy is about choosing goals and prioritising objectives; when the goals are carried out, implementation has taken place. However, if on the ground level the practice is significantly different from the goals specified in the policy objectives, either the policy has not been carried out due to non-implementation, or the goals have not been clearly explicated in policy documents for some reason and non-decision making has taken place. It becomes critical therefore for our deeper understanding of the non-inclusion of disabled children in the ICDS policy to examine how initially the policy got formulated for example whether the issues concerning disabled children were discussed at all while the objectives of the programme were being drawn up? Why did certain issues not come up on to the policy agenda? What are the wider latent issues?

PART TWO

THEORETICAL AND CONCEPTUAL FRAMEWORK

4 LITERATURE REVIEW: GLOBAL INITIATIVES AND INDIA

Introduction

Having tracked Indian policy and practice through the last fifty years, it is important to find out what was the policy and practice like for under-five disabled children in other countries. Chapter 4 continues the review of literature, and examines the theoretical notions behind the critical first five years, the importance of these years for the disabled child as well; the various measures of intervention which have taken place through policy change, educational reform and legislation; the global initiatives that have ensured that disabled children get access to equal educational opportunities in the last two decades. The aim of this chapter is to seek evidence of the importance of pre-school intervention for disabled under fives, and the wider issues that contributed in bringing disabled children into the network of existing provisions. The review broadly examines policy-making in two countries, the UK and the US, and how critical issues got identified, spearheading Government action, through legislation and mandate. The reason for examining the developmental literature for the age group of 0-5 is because of the ICDS policy and its target group, the aim being to draw some insight about the gap in the disparate pre-school services that exist for the normal and the disabled child in the Indian situation.

4.1 The Critical First Five Years

There is voluminous literature showing that the first five years of a child's development constitutes the most critical period of his or her life. Valuable contributions have been made in the field from all disciplines such as the

neuroscience's, paediatrics, the social sciences, psychology, education and from the psychoanalytical school (Griffiths 1970; Sheridan 1975; Myers 1992; Sylva and Lunt 1982; Woodhead 1996).

Whether the child is happy and stable in this period or unhappy and out of step with society, or with his lessons largely depends on one thing - the adequacy of his early nurture (Ministry of Education Report 1955 on Children Department Notes, UK).

It has also been shown that there are certain critical periods in the child's life, when it is able to absorb the optimum, and if these periods are not triggered off with appropriate experiences during the optimum periods of learning no amount of training later helps the learning processes.

In the UK, one of the most important documents relevant to the pre-school period, the Plowden Committee Report, *Children and their Primary Schools* strongly stressed early education and the concept of certain critical periods in a child's life when clear reasoning is at its height.

...that at certain times, responses to the environment are potentially dramatic and which if not made at that stage might be missed for ever (Plowden Report 1967).

The rationale for early intervention was also influenced by Bloom's interpretation of longitudinal studies of intelligence from which he concluded that 50 per cent of the variance in intelligence at 17 years is determined by the age of four and 80 per cent by the age of 8.

Modern research also reinforces the theory that the most formative years are before the child comes to school. Sylva (1993) defines early learning as learning which occurs outside the home before the child enters formal school. The scope is limited to learning that takes place in nursery schools and classes, day nurseries or child care centres and playgroups (Sylva and Wiltshire 1993). Writers suggest that early learning experiences, produce immediate measurable gains in the cognitive and social development of pre-school children (Myers 1992; Sylva and Wiltshire 1993;

Woodhead 1996). Writing about children in socially disadvantaged situations, Myers (1992) argues that,

Poverty and discrimination produce stressful conditions and unequal treatment that can inhibit healthy and comprehensive development in the early years. Children from poor families often fall quickly and progressively behind their more advantaged peers in their readiness for school and that gap is never closed (Myers 1992:10).

Sylva (1993) reiterates that,

The impact of early education is found in children from all social groups but is strongest in children from disadvantaged backgrounds (Sylva and Wiltshire 1993:37).

Research in the United States of America amongst a deprived population showed that investment in high quality and effective early education provided a worth while social and economic return to society showing that, out of every hundred youngsters with good pre-school education, forty-eight managed to gain employment, and forty-five were able to support themselves completely on their own earnings; while out of every hundred without pre-school education, the comparable figures were twenty-nine and twenty-four. In addition to economic argument, the American High Scope Study, revealed that seventy-one percent of those on a good pre-school programme completed twelfth grade better than fifty-four percent who had been denied it (Weikert 1978).

However, there has been some scepticism about whether or not early learning effects of pre-school experience continue, or 'wash out' soon after school begins. Woodhead (1994) argues in the British Psychology Society's Education Section Review that,

...one of the most consistent findings is that early education does not in itself produce a long-term change in children's cognitive abilities. Yet in a whole series of

key indices of social adjustment and general life competence the pre-school programme appears to be a resounding success (Woodhead 1994:47).

On the whole, however, it would be true to say that research on child development now indicates, that the early years are crucial for the social, emotional, psychological and cognitive development of the child. This is much more rapid during the early years and not surprisingly, the effects of deprivation have been found to be greatest during the period of most rapid growth. This in turn has resulted in a growing conviction that by providing better and more stimulating environmental conditions children may get a better start in life (Blackstone 1971; Murlidharan 1991; Sylva and Lunt 1982; Bell 1994; Saraswathi and Kaur 1993; Kaul 1994).

Knowledge about what to do to foster healthy and holistic child development has accumulated, providing an adequate basis for action (Myers 1992:437).

Now the controversy is no longer whether early learning matters. There is substantial evidence to show that it does matter, and that in fact a rich stimulating environment leads to immediate and lasting social, educational and economic benefits for all children, especially those from disadvantaged backgrounds (Myers 1992; Woodhead 1976; Sylva and Wiltshire 1993).

4.2 The Critical first five years and implications for disabled children

This argument holds true for 'all' children, *including disabled children*. In fact the consequences of inadequate stimulation at an early age, are even more disastrous than for non-disabled children, as it is during this period that the disabled child stands the best chance of improving abilities and developing efficient 'compensatory' patterns. Stukat (1978) suggests that since

During infancy the child is most adaptable and impressionable and basic patterns of behaviour are formed, in fact the consequences of inadequate stimulation at an early age are even more disastrous than for non-disabled children. During this

early malleable phase the child with disability stands the best chance of improving disabilities and impaired functions (Stukat 1978:5).

During this 'critical period of development' (Stukat 1978:5), the child needs intense stimulation for optimum development. He suggests that this is crucial in order to avoid permanent retardation or secondary handicaps from happening (Stukat UNESCO 1978).

Scandinavian experience, with concepts of normalisation and integration of disabled people into the community, reiterated this. Jorgensen writes that special educational assistance should begin as early as possible. In Denmark, in 1969 the Danish Parliament decided that this assistance should be provided in such a manner that the children might stay in their own environments (Jorgensen 1979).

Canadians too adopted the philosophy of normalisation and the principles that stem from it, regarding the provision of integrated services for disabled people. In most of the developed countries, various early detection tests are carried out when the child is born, to determine whether the child is 'at risk' of developmental delays, which may lead to a handicap (Stukat 1978; Jorgensen 1979).

We have for some years been in a position to see what harm institutionalisation does to a child at birth and how important it is for the disabled child to live within his or her own family circle. We have come to recognise the need to provide such a child with suitable care facilities at the earliest possible age (Bouchard 1978:26).

It has been stressed that the family is the child's most valuable asset (Bouchard 1978; Stukat 1978; Potts 1984).

Potts (1984) stressing equality of opportunity writes,

For children under five, integration is the process of increasing their participation in the life of the community, through being based in the playgrounds and nurseries and nursery schools and classes within

mainstream education. It is the practical consequence of holding to the principle that children share an equal right both to membership of the same groups and to the varying levels of resources that they may as individuals need. Integration involves making ordinary groups more comprehensive and therefore an issue, which concerns all children (Potts 1984:1).

Bricker (1979) writes about the philosophical aspect,

Education is one of the primary mechanisms for the transfer of social values from generation to generation therefore it seems appropriate that social-ethical considerations form the basis for the first arguments for exploring the integration of disabled and non disabled pre-school children (Bricker 1979:4).

However she goes on to say that arguments based on a social consideration depend heavily on established social values which may be difficult to articulate and defend from an empirical perspective (Bricker 1979).

Thorburn (1978) reports that in most developing countries though they may invest in special education services, they do not provide services for the pre-school age group. There were a number of reasons for this, some of which are valid, others based on misconceptions. The more valid reasons for this were costs, lack of trained personnel, lack of an infrastructure, a lack of a system within which to develop such services (Thorburn 1978:60); which brings us to the wider question in some countries of having systems which are selective and educational priorities culturally determined (Potts 1998:114).

Another factor to consider, argues Bricker (1979) citing a parent of a disabled child, is the attitude of society towards people who are different.

Society does not view their (parent's) children as worthy of investment: in fact, it disdains those with certain handicaps. The parent, in turn, feels devalued

(Gorham et al 1975: 154 cited in Bricker 1979:7).

Often it is not a lack of resources but as Gorham et al (1975), a group of parents, state,

The real obstacle may be the average man's unwillingness to spend it on 'persons who are different.' A lack of money is not really the obstacle that keeps children from reaching their potential (Gorham 1975:156 cited in Bricker 1979:7).

Handicap is a relative term. Handicap is not only dependent upon the extent of disability or impairment, but also upon the expectations and standards set up by Society or 'other people'. These standards tend to be intolerant towards 'deviation' from what is considered the 'norm' (Foucault 1976). It is argued that long-term programmes should not only help disabled children adapt and adjust to normal society, but make society ready to accept individual differences and variations (Stukat 1978; Oliver 1990).

Early care cannot be limited to institutions or to the exclusive care of a few specialists. Stukat (1978) states that joint action involving 'the family, the schools and the community has to be a common responsibility and an interacting team is the most natural model' (Stukat 1978:137). Highly sophisticated, over-technical jargon makes the parents feel alienated when they are needed to work together with the specialists, in partnership. To increase awareness in parents and knowledge is an urgent and challenging task. 'Deprofessionalisation' may be desirable for more efficient communication (Stukat 1978:138).

What comes across strongly from the studies and research done, is that intervention for children with disabilities should begin as early as possible, and, that if a disabled child is left without proper management and care, there is a high probability of secondary effects developing, which can be harmful for the child's development (Stukat 1978; Bricker 1979; Potts 1984).

4.3 Pre-school integration for disabled children in the UK

In 1967, in UK, the Plowden Report on 'Children and their Primary Schools' highlighted extensively the educational implications of the socially disadvantaged. Plowden recognising the cumulative nature of some children's disadvantage, argued that some children were at a two-fold disadvantage, not only because of the circumstances of their home, but also because of their schools which tended to be in poor areas with poor facilities. In 1972, Government brought out a White Paper on Education, called 'Under fives a Priority... a Framework for Expansion'. It recommended that free part-time provision be made available to all children aged between 3-5 whose parents wanted it. However, there did exist conflicting views about pre-school provision: day-time provision for young children was seen as compensatory to make up for what was lacking at home (Mittler and Mittler 1994; Newall and Potts 1984).

In 1978, the Warnock Committee Report, another landmark in the history of pre-school education, listed essential provisions for children under five, with disabilities as one of its three top priorities (Warnock 1978). The crucial importance of early educational opportunities for children with special educational needs was recognised and the role of parents as educators and therapists gained much currency. The reasons given were that early identification prevents special needs developing later by detecting children who are 'at risk'. Great emphasis was placed on the earliest possible intervention, suggesting that every effort should be made to absorb disabled children into nursery schools in the areas where they lived.

Duties to identify disabled children start from birth. From the age of two the full duties of the 1981 Act apply, that is. to identify, assess and provide for children with special educational needs for whom they are responsible (Potts 1984 citing 1981 Act:1).

The Education Act, 1981 reiterated that no disabled child should be sent to a special school 'who can satisfactorily be educated in an ordinary school'. The Act gave parents more opportunities than before of participating in decisions affecting

their children's education. The crucial importance of early educational opportunities for children with disabilities was recognised and the role of parents as educators and therapists gained much currency (Mittler and Mittler 1994; Newall and Potts 1984).

Potts (1984) reports that provisions for under fives are more community-based and in many places across the country children with disabilities are already included in a variety of non-specialised groups, such as playgroups, opportunity classes, toy libraries, parent groups, nurseries, home visit schemes, and short and long-term care schemes, play schemes, provisions which involve the under five disabled children and their parents (Potts 1984).

The benefits for young children from economically disadvantaged backgrounds have been clearly demonstrated by studies from the US and the UK (Mittler 1994); and recently the argument for the extension of pre-school education to larger numbers of children, has been greatly strengthened by the recommendations of the National Commission on Education (1993). It has been suggested that supplying pre-school provision is not only a matter of long term gains for families or for society, but of meeting immediate needs of young children whose development may otherwise be adversely affected (NCE 1993).

4.4 Pre-school integration for disabled children in the United States

The Head Start Programme

In 1964 Lyndon Johnson, then President of the United States, with his 'war on poverty' cry, launched a massive programme called Head Start. Head Start had its origins in an optimistic period of American History, when many believed that Government should take an extensive proactive role in eradicating the negative effects of poverty on children's development, mainly from the culturally deprived families of the Blacks and the Hispanics (Little and Smith 1971). Massive funds were put aside for educational programmes that would be compensatory. Zigler and Muenchow, (1992) report that in 1964 the US Council of Economic Advisers reported that much of the country's poverty, was to be found in physical and culturally isolated rural and

urban areas and that half of the thirty million poor people were children. These daunting statistics were thought to be responsible for the rise in crime rates and violence and a decline in youth readiness in playing productive roles in the military and in industry (Zigler and Muenchow 1992).

The Head Start Programme opened 3,300 programmes for thousands of children right across America, with the aim of improving children's intellectual, social and emotional development and expanded at an unprecedented rate (Zigler and Styfco 1993). Interesting and relevant for this investigation is the fact that Head Start is one of the largest programmes in the world where disabled children were first admitted, and the fact that Federal mandate required that at least ninety per cent of the children admitted, were from families whose income fell below poverty line; at least ten per cent of the enrolment had to consist of disabled children (Little and Smith 1971; Zigler and Muenchow 1992).

Head Start did not achieve all the objectives it set out to do, and came under heavy fire. The main criticism against Head Start was that the advantages of the programme faded after two to three years. In 1957-1966 focussing on Blacks, the US Commission on Civil Rights concluded that such programmes could be helpful, but there was no evidence that they significantly raised the achievement levels of the group as a whole (US Commission on Civil Rights, 1967). Clearly Head Start had unrealistic goals and was expected to achieve far too much.

However, there were many positive gains. The High Scope Cognitively Oriented Curriculum showed innovative studies working with parents and infants from the three-month level. Some Head Start Studies showed increase in general abilities and achievements. Participant children performed better immediately after the programme than non-participant children. Increase has been the greatest when the programme was of longer duration. The Follow-Through Programmes showed that continuity produced good long-term results. The longitudinal evaluation of the Head Start Programme showed positive gains. (Rhine 1981:201). Long-term follow-up studies of children originally involved in pre-school Head Start projects in the late 1960s suggest that these children are 'much less likely than controls from similar backgrounds to be referred for special education. They tend to remain at school

longer, show higher employment rates... these gains are all the more remarkable because the early results of the programmes were originally thought to be disappointing largely as the earlier programmes were looking for gains in terms of IQ scores' (Mittler 1994:61).

Parental involvement increased. Poor people got an opportunity to be placed in college and universities to pursue professionally recognised courses in childcare. Head Start also led the way in social ways and was able to create a cadre of socially involved leaders among the minority groups.

The fact that over hundred universities in America got involved in innovative research and evaluation has been a major contribution, placing the focus on the problems of disadvantaged children and integrating disabled children. As for the Indian situation, Jangira (1995) reports a major lacuna in this area, as except for one or two universities, no universities have departments of Disability Studies. Jangira (1995) writes that one of the major impediments in India is that there has been an extreme shortage of staff; training being done only by a few voluntary institutions as well as the National Institutions run by the Ministry of Welfare. The training programmes by and large have been outside the ambit of the universities (Jangira 1995).

In 1975, the Education for All Disabled Children Act in the US was enacted which mandated that free, equal and appropriate public education, must be provided between 3 - 21 years for children and people with special needs. The regulations required that:

To the extent appropriate, disabled children, including children in public or private institutions or other care facilities, (shall be) educated with children who are not disabled (Education for All Disabled Children Act 1975 cited in Bruininks 1985:12).

The concept of normalisation in which disabled persons were to participate, was referred to as placement in the 'least restrictive environment' (LRE). The process of

normalisation in a least restricted environment, would include provisions for disabled persons according to need and

should be, to the maximum extent possible, provided in the types of community settings that are used by non-disabled persons (Ibid. 1985:12).

Legislation had far-reaching effects in the United States. The Act required States to provide educational and other services to disabled children between the ages of 3 and 5, and in fact encouraged them to do so from birth.

In the 1960s the term 'compensatory education' came into vogue. It was used to describe education and social measures taken at solving problems associated with children from socially disadvantaged groups, children, who by reason of their impoverished backgrounds were educationally retarded as well and were considered at high risk of being wrongly labelled as mentally handicapped. Compensatory education was supposed to be a preventive form of intervention with children from socially disadvantaged backgrounds.

Advocates of compensatory education tend to insist, that it should be begun as early as possible, and this form of intervention is usually begun during the pre-school years. Chazan (1979) argues that the earlier one starts, better are the chances of alleviating learning problems and preventing children from being put into special classes, whereas remedial education tends to be a 'piecemeal strategy' usually needing a one to one intervention, compensatory education is a group intervention technique, using the evidence of correlated studies to identify children at risk. The main philosophy behind it is to use it at an early age as a preventative measure to stop children from later failing in school and dropping out or falling into the 'net' of the remedial teacher (Chazan 1979).

Disabled children were included in this 'net'. The additional factor, which strengthened the LRE concept, was that recourse would be provided in law, in the event of 'disagreement about the appropriateness and/or restrictiveness of placements' (Bruininks 1985:13).

The United Kingdom was very much influenced by compensatory education carried out in the US. The Plowden Report (1967) extensively described the educational needs of pre-school children and recommended that pre-school children in the very deprived and poor sections of the cities were given priority. These schools were later called the 'educational priority areas' or the EPA schools. Local authorities were asked to adopt a policy of 'positive discrimination.' However, in the UK, the system retained much of its original popularity, partly because the programme itself and its objectives were far more low-key than the Lyndon Johnson experiment. In addition, the EPAs stressed the home as much as the school, and it is the home which many educationists see as pivotal to the success of maintaining a continuum in schooling.

The focus should not only be the child. Chazan (1973) argues that the school should really be the target of change, and 'that compensatory education tends to detract the focus from the school to the deficiencies of the community, the family, and the child' (Chazan 1973:14).

A consistent body of evidence indicates, that a pre-school compensatory education programme has more staying power if parents are involved; if the programme is sustained at the primary school levels, and if the community and neighbourhood participate in the programme. It certainly seems good educational practice to give attention to the individual child, the family unit and move on to the milieu or community in which he or she lives, thus building up a 'triangle of care' (Sylva 1994). Mothers and family participation emerged as the main recommendation of the American and British Studies. Finally, when designing a programme, it was more than clear that one must keep the goals and objectives small and few in number, a lesson learnt from the American experience, and that a project can run into troubled waters if overburdened with too many goals.

Substantial studies now indicate that if a child is disadvantaged through some adverse circumstances, be it poverty, disability, or membership of a minority community, the child sustains various kinds of damage which put him or her at a severe disadvantage with its peer group. It has also been widely recognised that by the time a child is 6, when most children enter school, it would be too late to remedy

deficiencies if any, thus causing irreversible damage (Chazan 1973; Myers 1992; Sylva and Wiltshire 1993; Woodhead 1996). What is of particular significance for this study are two issues: that legislation was enacted and priority was given in the UK and the US to under five disabled children, in areas of pre-school and treatment from the age of 2, making it the responsibility of the State to ensure suitable provision; second, pre-school intervention using principles of compensatory education, was used to reduce the chances of children from socially deprived homes from dropping out and failing at school, as a preventive strategy in the early years, and this included the disabled child as well.

4.5 Integration: historical and an ideological perspective

Compared to the non-industrialised countries, the countries in the industrialised world seem to have moved forward in the education of disabled children. A greater awareness about disabled children had developed, and there was a shift to include them into mainstream environments. How did this all happen?

The literature documenting the beginnings of provision tends to stress it as the 'charitable' and the 'good' development taking place for humanitarian reasons, as we have seen happening in India. Oliver (1985) has described that disability was seen as an individual's problem, a personal tragedy and a tragic event, and disabled individuals had to learn to adapt to society.

This humanitarian element was rooted in the traditions of social reform gathering facts about disability, policy decisions were based on the collections of facts and these decisions underpinned by humanitarian concerns (Oliver 1985).

Current research shows that the shift took place as greater awareness developed about disabled children and a strong trend towards normalisation of experiences gained pace. Although children were in special schools, from as early as 1950 new concepts of handicap were emerging. There was a growing concern for human rights issues, leading to active campaigning and lobbying to provide disabled children as normal an environment as possible. The Warnock Committee of Enquiry advocated a

system of education (similar in tone to that of the Sargent Report in India in 1944) whereby,

... so far as possible, children suffering from all types of disabilities are educated in ordinary schools. Such children previously labelled as physically or mentally disabled should be fully integrated into ordinary schools and measures be taken to dispel the stigma attached to special schools (Warnock 1978).

Baroness Warnock recommended that the concept of handicap be substituted by that of special educational needs. On April 1, 1983 Parliament enacted the Education Act of 1981, which adopted many of the 224 recommendations, made by the Warnock Committee.

A new language of disability

In an effort to dispel the stigma associated with the labels of the past, the old language which labelled disabled people as 'lame' 'defective', 'cripple' was abandoned and replaced by the new language whereby children with disabilities were described in broader more general terms such as 'children with special educational needs'. The idea behind this was that the traditional categorisation of handicap or the old language of handicap, confused pedagogic planning and had little or no relevance to the delivery of service (Wedell 1984; Evans and Varma 1989).

The old language of disability, it was argued, implied a mistaken model seeing difficulties 'within the child' (Wedell 1984) and disregarding the numerous facets of the environment which disabled the child. The definition of 'special educational needs' in the 1981 Act marked a change from 'within the child to an interactive view',

Special educational provisions means provisions which are additional to, or different from, educational provisions made generally (Warnock 1978).

Wedell (1987) and colleagues wrote,

In other words special educational needs are the outcome of the interaction between the resources and deficiencies within a child and the resources within the environment (Wedell et al 1987).

The term 'learning difficulty' is now commonly used in order to reflect a functional rather than a diagnostic and medical orientation. Clearly there has been a change in nomenclature and a shift away from any kind of labelling and compartmentalisation, and it is now believed that labelling individuals according to a type of disability focuses on the individual's deficiencies emphasising the negative aspects of his situation (OECD 1994).

Detailed multi-disciplinary assessment of children was stressed. A 'continuum of needs' was recognised and a close co-operation between special and ordinary schools suggested. The role of 'parents in partnership' was emphasised as critical. The Warnock Committee distinguished between three forms of integration. *Locational* – that is, special units or classes in an ordinary school or a special school on the same site as an ordinary school; *social* – where locational integration exists, but social interchange also takes place between special and normal; and *functional* integration which involves special children almost joining their normal peers in regular classes on a full-or part-time basis (Warnock 1980). 73

The years that followed saw the enactment of legislation in many countries: Sweden, Norway, Italy, United Kingdom, Denmark, France and Germany seeking integration or mainstreaming of children with special need (Hegarty 1982). Thus in the European context, Jorgensen (1979) reports on developments and trends within the European Community as being 'fairly homogenous' (Jorgensen, 1979).

Writing about the historical evolution that took place Cole (1989) recounts that initially it was voluntary effort which made good the deficiencies in provision that existed. Then followed the intervention of government to create a national framework in which public and voluntary agencies acted in partnership to see that all children, whatever their disability received a suitable education (Cole 1989). As the trend towards normalisation of experiences for disabled children gained pace, people began to question the efficacy of special schools.

The impetus for both integration and inclusion comes from a concern for the rights of children and young people (Wedell 1995:1).

Groups of disabled people and parent pressure groups spoke vociferously about the needs for normalisation and tolerance from society as a whole. 'From being a rallying cry for those with a vision for change in special education, it became the new orthodoxy' and special schools not integration initiatives had to justify their existence (Hegarty 1984). However, the subject of segregation versus integration generated many debates. Those against integration argued, that the old categories with their negative labels had created appropriate education for disabled children provided properly resourced environments, with people who understood them better. This was not always available now in the regular schools.

Research indicated that children with disabilities who are enrolled in integrated early childhood programmes demonstrate higher levels of social play and more appropriate social interaction and are more likely to initiate interactions with peers than are children in self-contained special education prescribed pre-school classes (Lamorey and Bricker 1993). Integrated classes offer more opportunities for children to practice using a newly acquired skill with their peers than do self contained special education classes (Demchak and Drinkwater 1992). Guralnick and Groom (1987) compared the behaviour of pre-school children with mild mental retardation in integrated and segregated play groups and found that children with disabilities in the integrated groups participated in twice as much social interaction and displayed higher levels of play, than did children in the segregated groups (Guralnick 1990). Pijl and Meijer (1991), report that quite a number of handicapped students in Europe, are currently being kept in special schools segregated from their peer group. The integration of these children involves considerable changes in areas of transport, buildings, teacher support and attitudinal change. These are dependent to a degree on funding and to teacher training, and all of this depends on attitudes changing (Pijl and Meijer 1991).

Evans (1995) writing about integration in the OECD countries, argues that 'it can be concluded, albeit tentatively, that integration is cost-effective and also offers the

possibility for a more flexible use of precious funds for the benefit of all students' (Evans 1995:217).

4.6 The wider policy framework

Integration happened due to the changes in the wider educational system that had evolved. In Britain, the change evolved mainly because of *a growth in the understanding* of children with disability, resulting in *a change in attitude* towards the disabled over a period of two decades, and followed by Acts of Parliament (Wedell 1993). Stress was laid on the *development of equal opportunities*, valuing all students equally and considering integration as the fulfilment of comprehensive principles (Booth 1983). The challenge has become to examine ways and means of including *all* pupils who are different or diverse in any way; a system that ensures 'equality of value' which 'combines the principles of comprehensive as well as integration principles' (Booth and Potts 1983); 'a whole school approach where all children regardless of their capabilities, background, interests or handicap are admitted' (Booth and Potts 1983:27); to have an educational system which accepts the 'ownership of any kind of diversity' and accepts the principle that the aim of education should be to include all children (Wedell 1995:1). Inclusive education was about minimising exclusion and fostering participation for all students in the culture 'for a wider support of children in ordinary schools' (Booth and Potts 1983). 'Success depended on a school being prepared to cater to individuals rather than just offering standard programmes, involving members of the broader community in decision-making' (Evans OECD 1995).

Research also indicated that attitudinal factors could be major barriers to integration. These can be attitudes of teachers, peer group, parents themselves. The negative picture seems to dominate (Jenkinson 1993; Stukat 1993; Williams 1993). However, Booth (1983) argues, while writing about severely disabled children that prejudice whilst it could prevent the establishment of programmes, once set up 'reduces considerably' (Booth 1983:21). Again, substantiating that negative attitudes can be turned around, Hegarty (1993) reports that

Various studies have investigated the process of attitude change in relation to disabilities: the evidence is that structured programmes can yield positive outcomes but the area is not sufficiently understood yet (Hegarty 1993:199).

Values and ideological systems

Christensen (1996) writing about issues of social justice has argued that,

Disability is one of the most frequently forgotten forms of social political and cultural oppression (Christensen and Rizvi 1996:66).

Christensen and Rizvi (1996) succinctly sum up the issue of equity when they write that 'autonomy is something granted to persons who are valued'. For persons with disability, autonomy is limited by at least three factors: these being limitations inherent upon the impairment, broad societal attitudes towards persons with disabilities and the nature of current human services practices (Christensen and Rizvi 1996). Indeed the authors feel that the

... compassion view of social justice sits uneasily with the access, equity and empowerment views (Ibid. 1996:152).

The former views, they stress are motivated by care, concern and compassion for those in society who are seen as 'less' fortunate (Ibid 1996:152). The authors argue that 'this leads to client helplessness and in fact contradicts views of social justice linked to the idea of autonomy and empowerment' (Christensen and Rizvi 1996:152). About societal attitudes, US. Supreme Court Justice William Brennan wrote in the case of School Board of Nassau County versus Arline, that:

Congress acknowledged that society's accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment (Lipsky and Gartner 1996:152).

Tomlinson (1982) and others have argued about the social origins of special education suggesting that the treatment of those described as handicapped is dependent on the values and interests of dominant groups. Prevailing cultural values influence situations (Tomlinson 1982; Potts 1998; Miles 1998).

Fraser (1995) argues about the dimensions of social justice as being cultural in nature.

The second kind of injustice is cultural or symbolic. It is rooted in social patterns of representation, interpretation and communication. Examples include cultural domination (being subjected to patterns of interpretation and communication that are associated with another culture and are alien and/or hostile to one's own); non-recognition (being rendered invisible via the authoritative representational, communicative and interpretative practices of one's culture); and disrespect (being routinely maligned or disparaged in stereotypic public cultural representations and/or in everyday life interactions) (Fraser 1995:71 in Christensen and Rizvi 1996).

Rejecting individualized 'personal tragedy' accounts of disability and impairments as 'disconnected', and having structural and cultural antecedents, disabled researchers sought the development of the social theory of disability (Hahn 1985; Finkelstein 1980; Oliver 1988, 1990; Abberley 1987). Defining and mapping differences according to categories of disability they argue, were in keeping with 'governmentality' and regulations concerning subnormal people (Foucault cited in Christensen and Rizvi 1996).

From the study of the documentation, in conclusion, one can say that integration of disabled children even in the West has not been fully successful. There still exist some very real constraints in integrating children with special educational needs. The West has not an absolute unified way of working. The constraints of integration differ from country to country. In Britain, the stigma of labelling is present. A group of children within schools who have special educational needs are 'statemented' or assessed and sometimes separated from others, in units within the school with the

procedure of labelling which according to Tomlinson (1982) reflects an 'individualistic approach to difficulties and handicaps' and highlights differences rather than ignoring or adjusting to them. This results in children growing up nursing differences, and teachers and students have problems of accepting these differences. Hegarty (1993), reviewing the literature on integration argues that although integration has been a key issue for twenty-five years, there has been between what has been stated and what has been implemented a gap that he has attributed to various factors. To mention some of them,

... the pedagogical limitations of many ordinary schools, the imperatives of a national curriculum, the magnitude of the task, the inertia in the educational system, the resource allocations mechanisms (Hegarty 1993:195).

Progress, he argues, has been uneven and this is partly due to the difficulties in bringing about a systems change. He suggests that,

Integration may be unable to develop beyond a certain level; ordinary schools can go a certain distance in accommodating students with special needs.

It may be that the aspirations of yesteryear were set too high and we have to accept that there are limits to integration (Hegarty 1993:195).

It has however brought about a sea change in attitudes, a shift in ideology, which has been translated, into action through Acts of Parliament. This has resulted in the development of codes of practice, and implementing mechanisms, translating policy into practice. It has brought in the issue as a matter of right, with the option of a choice for parents to put their child into a normal or special school. It has taken on board the issue that disabled children can no longer be segregated and isolated on grounds of disability. All this has been possible, because of an ideological commitment to the philosophy of equal opportunity, and the fact that societal change at all levels is critical in mainstreaming disabled children and their families as part of

the larger community. These are the issues, currently a matter of fundamental concern that need to be addressed if positive integration is to happen.

4.7 Mainstreaming pre-schoolers in a few developing countries

Thoburn (1998) reports about attitudes towards childhood disability in Jamaica that supernatural beliefs were held by a significant minority of Jamaicans, that disabled child 'were sent by God'.

These beliefs are significant, if held by parents, as they may interfere with intervention efforts or may encourage isolation and 'putting away' the child (Thoburn 1998:20).

In the survey of three areas in Jamaica, she found that the most significant barriers were persistent supernatural beliefs, lack of awareness of the possibilities, and a persistent belief that special institutions are the best. There is more literature on integration and research methodology in the North countries (North of the Equator) than there is in the Southern ones (Miles 1996). However, a review of the brief literature available of integration projects in developing countries shows that in India, China, Thailand and Jamaica, encouraging work has begun in mainstreaming pre-schoolers according to each culture specific context.

(i) Dharavi, Bombay

In Dharavi, Bombay, the Spastics Society of India began a demonstration model of integration with hundred children, fifty children of whom were able-bodied and fifty with disability. The disability was mainly physical disability: children with polio and cerebral palsy. The main objective was to bring inclusive education into a community setting. The children were brought in two shifts and twenty-five children put into each group. The parents of the disabled children were initially reluctant to integrate. This was reported to be short-lived; as they experienced the effects of integration, and observed that all children played together and their disabled child was a part of the play, they became positive towards the idea, and began to bring their children in

regularly. The project is a useful demonstration model for teachers, parents and the ICDS administrators (The Spastics Society of India, Annual Report 1997).

(ii) Lok Jumbish, Jaipur

Lok Jumbish in Rajasthan, is a non government organisation, which has a programme being implemented in 83 villages spread over three clusters, one each in Rajgarh, Sagwara and Pratapgarh. The Spastics Society of Northern India is the resource agency for this programme. The programme involves participative development work, which involves parents and field level workers in developing awareness about the needs of disabled children. The target group is 3-14 year olds and 474 children with disability have been identified and efforts are being made to integrate fifty percent of the children (Annual Report 7 1998).

(iii) Anhui, China

Save the Children Fund, began inclusive practices in a few developing countries. Holdsworth (1993) reports, about the Anhui Provincial Integrated Educated Project, China, that the Provincial Education Commission began with two pilot projects. The results reported were encouraging. Most of the children did well and those old enough were successfully moved on to local primary schools at seven years. Great care was taken to build strong partnerships with families so that school and family work together and the child can be supported both in kindergarten and later at primary school. Training of teachers and administrators could be done within the province by using the pilot project kindergarten as a base. An important aspect of this was the training of county and city administrators. The basis has been laid for replication across the province, and whilst this may take several years to accomplish the model will act as a demonstration of accessibility to education for many disabled pre-schoolers (Stubbs 1995 unpublished draft).

(iii) Bangkok, Thailand

In the Bangkok Primary School experiment, Bangkok, 'Save the Children Fund' had been involved in integrated education since 1988. They began by supporting the Rajnakul Hospital in integrating children with mild disabilities at the Bangkok

Metropolitan Administration's Vichutit and Ban Bangkapi Schools. The results of these pilot projects had proved successful in the social and academic development of children with mental disabilities within the normal setting. Teacher education in collaboration with UNESCO began in Chiang Mai, Suan Dusit and Kanchanaburi Teacher Colleges. The demonstration model has established that a possible integration programme must involve all sectors concerned locally, regionally and nationally if it is to sustain its activities (Stubbs 1995 unpublished draft).

There are many other excellent programmes of integration being tried out by numerous NGOs across the South countries, which go to demonstrate that it is a phenomenon *happening*. This investigation being restricted to policy and factors that have caused marginalisation to take place prevents me from reporting on these projects. However, the rationale for citing the few examples is to indicate that it is in a small way that all movements begin, and pioneering efforts to spear head Governmental action cannot be bypassed, as they have played a part all over the world, before State initiatives took over.

4.8 Global Initiatives on Equalisation of Opportunity: 'Education For All'

In 1988, UNESCO published *The Review of the Present Situation of Special Education* covering issues related to policies, legislation, administration and organisation, teacher education and financial provisions for special educational needs. Hegarty (UNESCO 1995), reporting on a review of special education in fifty-two countries, describes that the pattern of special educational provision varied greatly. In the majority of the countries (ninety six percent) the national ministry of education held sole responsibility for the administration and organisation of services. The other ministries sharing responsibilities were social welfare, health, and social development.

Relevant to the investigation is the fact that out of the four percent who had not responded to the Review, India was one: that India belongs to the four percent of countries on the world scene where disabled children are not a part of the national ministry of education; that India was amongst the minority of world countries where

the 'predominant source of funding' for 'educating disabled children' continues to be done by NGOs.

In 1996 UNESCO published the results of a world-wide survey of *The Laws relating to Special Educational Needs in Fifty-two Countries*. The nature and extent of special needs shows that forty-eight countries have brought in laws covering special educational needs. Special educational needs are the responsibility of the central government in forty-seven countries and the local authority in four. Relevant to the Indian situation, India had not once again participated.

Important international landmark developments that have taken place, which would influence the issue of disabled children, were:

- The International year of the Child 1981.
- The Decade of Disabled Persons 1983-92.
- The World Programme of Action in favour of disabled persons in 1983.

The following more recent ones were:

(i) The UN Convention on the Rights of the Child, 1989

177 countries worldwide have ratified the Convention on the Rights of the Child 1989. India was one of the countries. Article 23 is relevant to this investigation as it states the Rights of a Disabled Child to enjoy a full and decent life. It also states the Right of the Disabled Child to special care, education, health care training rehabilitation etc. (UNICEF, on the *UN Convention on the Rights of the Child*, 1989)

(ii) The UN Standard rules on Equalisation of Opportunities for Disabled Persons, 1993

The rules set out an international standard of policy-making and action covering disabled people. Special attention was to be given to the very young disabled children: pre-school children with disabilities and adults with disabilities specially women. In

order to implement inclusive education states should have a clearly stated policy that is understood at school and community level.

(iii) The Jomtien Conference, Thailand: World Conference on Education For All, 1990

In March 1990 delegates from 155 Governments (India was one of them) 20 inter governmental bodies, and 150 non-governmental organisations met in Jomtien, Thailand at the World Conference on 'Education for All' to discuss the basic learning needs of children, youth and adults. They adopted the World Declaration of Human Rights in 1948, which had enshrined the right of 'all' to education. The Declaration called for 'an expanded vision and a renewed commitment to education'. Little (1994) reports that this included:

- universalising access to education
- an active commitment to removing educational disparities between boys and girls, rich and poor, urban and rural, ethnic racial and linguistic majorities and minorities.
- Strengthening of international solidarity for the meeting of basic learning needs--a common and universal responsibility.

However questioning whether this was an admirable ideology or a false hope, Little (1994) cites one of the educators, Alec Taylor, from Montserrat who summed up the point succinctly in the conference,

Nine years to a new century and 'Education for All' is still a major issue. Are developing countries able to accomplish this in the closing years of the century? The issue has been raised for forty years and at the close of the century we are still tackling this question of 'Education For All' (Little 1994: 3).

Mittler (1995) argues that although it is vital that a national target be set, the prospects are not good as far as children with special educational needs are concerned.

There has been little or no reference to the education of children with special educational needs in two major follow-up conferences to Jomtien in India in 1993 (Mittler 1995). Hegarty (1997) suggests that the goal of education for all is a long way from being achieved in many countries and has to be accorded the highest priority and 'again it is all too easy for the education of those with disabilities to be deferred until other targets deemed more pressing have been met' (Hegarty 1997).

(iv) The World Conference on Special Needs Education, Salamanca, Spain, 1994

Soon after the Jomtien came the Salamanca Conference. In June 1994 representatives of 92 Governments and 25 international organisations formed the World Conference on Special Needs Education held in Salamanca. India was a part of this Conference. The Conference agreed to a new Framework of Action, which stipulated that all disabled children should be included into the regular schools. With a commitment of 'Education For All', as in the Jomtien Conference, the Statement said that regular schools were the most effective means of combating discriminatory attitudes, creating welcoming communities and building an inclusive society. The Statement called on the international community to endorse the approach of inclusive schooling. It asked the United Nations and all its specialist agencies, UNESCO, UNICEF, UNDP and the World Bank, for endorsement of this Statement. The Framework for Action said that 'inclusion and participation are essential to human dignity and to the enjoyment and exercise of human rights' (The Salamanca Statement 1994).

The global initiatives attended by delegates from India undoubtedly influenced the Government of India. Following the Salamanca Conference, one of the country's largest programmes, called the District Primary Education Programmes and supported by the World Bank, was set up. The main thrust is universal education and included among its wider objectives is the principle equalisation of opportunity and integrated education for disabled children.

Summary

Looking at what has been happening in the international scene, the important themes that come through mostly strongly are that disabled children under five should begin

education as early as possible, in fact without any minimum age limit. Studies indicate that all children, including children with disability, are sensitive to the quality of their environment and their development is affected by the same factors, such as social disadvantage, family and community values, and quality of schooling; that debates over segregation and mainstreaming in an ordinary school are related to wider ideologies of equal opportunity, and that the new approach now recommends access to a common schooling for all children, and *access* to a curriculum appropriate for all pupils. The importance of bringing in parents in the education of disabled children in the early years, wherever possible, as the main educators of their children, also seems to come through equally strongly and is of value to the Indian situation, where community based techniques are far more important, and less costly than institution based ones; the growing importance of the 'rights issue' has been strongly stressed by disabled activists; India had participated in International Meetings and signed statements of intent to include disabled children in their 'Education For All' endeavour. Emphasis today is on accessibility and equalisation of opportunity.

The next chapter analyses and synthesises these findings, and based on the theoretical insights of this search draws up a conceptual framework to guide the data collection.

PART THREE

THEORETICAL AND CONCEPTUAL FRAMEWORK

5 FINDINGS AND ANALYSIS OF THE LITERATURE REVIEW

5.1 The International Scene

The review of literature about the international scene shows the important findings of researchers, on the cognitive, social, emotional, cultural development of the child during the period 0-5 years. In fact there is now major evidence that the optimum time for learning basic skills is those critical early years (Newell and Potts 1984; Carpenter 1994; Sylva and Lunt 1982). There is substantial evidence recording the deprivation that children who are socially disadvantaged or disabled in some form or other suffer scholastically, linguistically and educationally. The various strategies of intervention, in attempting to remedy these, have been compensatory education, special education and remedial education: Western countries have invested vast sums of money into researching the causation of learning difficulties and the efficacy of various techniques (Bereiter and Engelman 1966; Chazan 1977; Woodhead 1976).

Substantial research now gives credence to the value of early identification and early education for all young handicapped children (Laporta 1978; Bowley and Gardner 1980; Potts 1984). Today it is imperative that children with disability have access to services from as early an age as possible to prevent the development of secondary handicap; in fact, we learn that although pre-school provisions for the normal child are patchy in England, showing great regional variance, services for the disabled children are statutory from the age of two (Laporta 1978; Newell and Potts 1984; Wade, Barrie and Moore 1992).

The literature review also showed the development and changes in policy that have taken place, around the 70s and the 80s in the industrialised countries, and the

Ministry of Social Welfare and the handicapped were removed from the Ministry of Education to become the responsibility of the Ministry of Social Welfare (Aggarwal 1992). The Ministry of Welfare carried on the same kind of functioning as the British Provincial Government, giving grants to individual institutions dealing with the care and training of the handicapped (Taylor and Taylor 1970; Miles 1994). This is somewhat similar to the development that took place in England when the Education Act of 1944 was passed, putting children with disabilities into rigid categories of blind, partially sighted, deaf, partially hearing, ESN (M), ESN (S) etc., when special schools existed for the epileptic, even the delicate. India too has eleven categories of disability that are officially recognised, for which special schools are provided by voluntary agencies and grants in aid are given by the Ministry of Welfare to these agencies.

There are only 2450 organisations working for people with disability (GOI 1994). Considering the huge numbers¹⁷ that exist, this is clearly not enough. On the whole there is a paucity of special schools. Consequently a scale of casual and unplanned integration is also taking place (Miles 1996), though no major study has been done about the efficacy of this integration.

Historically, what becomes clear is that although the Government's statement of intent about the need to integrate children with disability into the existing system of education exists, the practice to follow such intent is at best patchy. The Government has made isolated attempts, but there has not been any significant public debate on the policy of inclusion.

(i) Dichotomy between policy and practice

We find that although the Government, (with the HRD Ministry as implementing agency), has been working for the cause of Education for All and signing Statements at International Meetings as in the UNESCO Meeting at Salamanca, agreeing to the policy of integration for the disabled child through various programs, such as the DPEP or the PIED scheme, it continues its segregationary policy of promoting the

¹⁷ Proper numbers of how many disabled people there are are not available, but the Government commissioned special surveys in 1981 and 1991 and these indicate a figure of five per cent.

idea of special schools through their Assistance to Voluntary Organizations Schemes (via the Ministry of Welfare). This produces a dichotomy not in keeping with the declared policy of Education for All, resulting in ambiguities, serious contradictions, and blurring of intention which affects policy on the ground level as has been mentioned by several writers (Welton and Evans 1986; Fulcher 1989; Slee 1993).

This paradox is somewhat similar to the Australian model where Slee (1993) reports that:

... it is paradoxical to see the way in which resourcing in integration in Victoria is contingent on the labelling of individuals (Slee 1993:186).

He goes on to describe it as a 'conceptual fragmentation' which:

... continues to typify the individual gaze where the 'dysfunctional' individual is the focus rather than a model of educational delivery that takes all comers, as a model of inclusion (Ibid. 1993:186).

This 'conceptual fragmentation' although used in a different sense by Slee, seems to be an appropriate definition and explanation of the dichotomy that exists in the Indian situation, creating the divergent agendas and a lack of cohesion in the provision of services within two arms of the Government. This dichotomy leads one to infer that perhaps the Government is unaware of the dualism and the contradiction it is perpetuating, or alternatively is aware, but chooses to be silent on this issue.

According to Slee (1993), another complication that comes between policy and practice (which is similar to what is happening in India) is the way

... the application of integration policy reveals divergence between the stated and the actual function of integration (Slee 1993).

There is substantial evidence of this in the disparities that exist between the stated policy in the Government documentation and the continuing divergent application on the ground level (for example the ICDS at Dharavi). On a detailed examination of

governmental policy, we find that there are statements that have been made about the inclusion of the disabled children into the ordinary system. These however are divergent to the action being followed.

While policy makers may be discussing integration at the top level, practice at the bottom level reveals 'contradictions' and a lack of 'authentic movement' towards placing the disabled child into regular classrooms. Barthes calls this a 'discourse of concealment' (Barthes 1972:143). In reality, no convergence appears to have taken place towards creating a uniformity of action within Government's own departments.

(ii) Politics of disability

Policy is not made in a vacuum. Barton and Tomlinson (1984) write that policy issues are embedded in a broader and complex socio-economic and political context, which generally cater to the needs of the wider society. It involves the whole educational system, as well as professionals working within the system, rather than simply looking at it as the needs of individual children (Barton and Tomlinson 1984: 65-80).

There *is* a need to acquire wider social, historical and political perspectives on the policies, practices and processes which make up special education (Tomlinson 1982:2).

Universal education concerns age group 6-14, which India is working toward. Both the ICDS and the DPEP programs are functioning from the same Ministry of HRD and it is this Ministry which is working towards 'Education for All'; yet a policy has not emerged for inclusion of the disabled child in the pre-school program of ICDS. According to Slee, policy

... distortions, in part, stem from the silences in policy, that allow for divergent agendas to be inserted and pursued at various levels of the policy process (Slee 1993).

These 'silences' and 'concealment' seem to be dominating the Indian policy, thus perpetuating a paucity of discussion and debate on the subject.

(iii) Voluntary not State

Today, in India, a majority of the services for the disabled child is delivered through the voluntary sector. This has become official state social policy. The continuance of state supported special schools brings sharply into focus the contradictory Government approaches in maintaining special schools, as well as in attempting to integrate the disabled child into the regular school system in a piecemeal fashion. Work for the handicapped is still considered 'good' and humanitarian acts of charity (Tomlinson 1982). This has not helped creation of a rights or entitlements environment.

(iv) Micro not macro

Voluntary agencies, however excellent their services may be, can only serve on a micro level, providing services to the few who can access them. The voluntary sector has no doubt played a very active and vigorous role in introducing new concepts of education and services, but without continuous funding and good infrastructural support it has been grounded on a micro level.

Today, the vast majority of people with disability, nearly ninety-eight per cent (GOI 1994) remain outside the ambit of any service from the state.

(v) Policy and action

Policy is made and implemented at all levels. The way a policy gets defined and implemented, the 'policy implementation chain' (Hill 1980) the link between definition and solution, is a consequence of a much wider terrain in which the policy is discussed. Barrett and Hill (1984) suggest that,

The political processes by which policy is mediated, negotiated, and modified during its formulation and legitimization, do not stop when initial policy decisions have been made, but continue to influence policy through the behaviour of those responsible for its implementation, and those affected by policy acting to protect

or enhance their own interests (Barrett and Hill 1984:219).

Policy implementation cannot therefore be seen as a simple linear 'top-down' process (Bachrach and Baratz 1970; Welton and Evans 1986) but a flow of activity that involves interaction at all levels. They can be on the *central* government level, concerned with the nature and interpretation of policy or decisions involving allocating resources: on a *local* government level concerning local policy and priorities; or at the *level* of administrators and professionals (Goacher et al 1988; Hill 1993). In India too the 'policy implementation chain', (Hill 1980) would involve negotiations between the politicians, the civil servants, Central and State officers, government advisers, local authorities, non-governmental agencies and or service delivery personnel. Each level would have their own idiosyncratic way of functioning and own values, within which context the implementers of any policy would have to function, very similar to the model which Whitmore (1984) describes as a multi-dimensional model like the layers of an onion in which each of the layers come in contact with and influences other areas. It also involves a variety of actors and agencies, each with their own beliefs, value systems, interests and power bases. The central government operating from the capital, New Delhi, co-ordinating with the States set in the different regions: the local authorities or the municipal authorities, who would be actually involved in the implementation, the health workers and supervisors as in the ICDS program on the ground level would require many levels coming in contact with and influencing each other.

(vi) Professional Interest Groups

The people who are involved in special education are in a position to mystify others. Tomlinson (1982) suggests that special education is one of the most secret areas of education, in which 'confidential files' are the rule rather than the exception (Tomlinson 1982:8). According to Tomlinson (1982),

The rhetoric of special needs may be humanitarian, the practice is controlled by vested interests (Tomlinson 1982:73).

She has gone on to term it as '*benevolent humanitarianism*'. Professionals are the benefactors and clients the weaker members of society. Vincent et al (1996) citing Skrtic (1991) suggest,

This group in modern society who has the authority to interpret normality and is the group that has accumulated the power to define and classify others as normal and abnormal and to treat their body and their minds (Skrtic 1991a:22).

The development of special education during the twentieth century can be viewed in terms of the vested interests of professional groups, medical, psychological, educational and administrative, each anxious that their perspectives and influence should predominate, yet recognising a mutual interdependence. There has been a school of thought that professionals may be specialised in their own area but have clung on to their specialisation and created a mystique around them for their own vested interest (Tomlinson 1982; Barton and Tomlinson 1984; Barnes 1990).

The State's reliance on the voluntary sector in India, for the provision of piecemeal services, put the controls into the hands of a powerful professional group.

(vii) Depoliticisation

Programmes of poverty alleviation, caste and gender issues, rural welfare, take a higher priority in India (Harriss-White 1995). Although disabled persons are a part of these groups too, they are powerless as a group (Lukes 1974), other vulnerable groups in the country comprising of caste, gender, also in the Ministry of Welfare, have more power and political lobby. Indian society continues to split its community into the normal and the abnormal (Foucault 1976), into rigid categories, of those who are able bodied and those who do not fit into the definition of normal and are called abnormal and must therefore suffer a type of apartheid. Writers argue that individualising the situations that families have to face, as suffering from some 'private' troubles needing individual solution, locates the problem outside the public sphere of concern thus causing depoliticisation of the issue (Oliver 1988; Fulcher 1990; Vincent et al 1996).

Depoliticisation, Individualisation, and a concentration on technical solutions are seen as the main outcome of professional control (Vincent et al 1996:475).

Powerful professionals well placed and well educated, have introduced considerable technical skills into special education. However, to look solely for technical solutions rather than examining political or structural issues is a means that has been called the depoliticisation of a situation (Wilding 1982; Cole and Furbey 1994; Vincent et al 1996), which is what has happened in the Indian situation.

On examining the historical development of services for the disabled child in England, we find that before state intervention could happen, individuals and religious missionaries introduced social reform, and this usually spearheaded the State into action (Cole 1989). Similarly, in the Indian scenario, at a certain point of time in history, the helpless and forgotten disabled child needed urgent care and education. In the absence of State policy and intervention such children's needs were met by individual action, charity and philanthropy, through the voluntary sector, introducing special education for different categories of children. However, we also learn from the review of literature that concentrating on the technical needs of disabled children and segregating them in special school situations, removes the issue from the public arena, absolving the state of responsibility (Kirp 1982; Barton and Tomlinson 1984; Oliver 1988; Vincent et al 1996).

(ix) Conceptual weakness

Tracking Indian social policy to get an insight into the marginalisation aspects of the ICDS policy, one sees acknowledgement of the needs of children with handicap right from 1944 and the broad philosophical affirmative statements on paper to meet these educational needs within the regular school system. However the implementing procedures of the two Ministries concerned have a dualism (Welton and Evans 1986) of purpose causing ambiguity in the field. The reliance on NGOs makes the work isolated and piecemeal, moving away from the issue of provision, entitlements and right; from a macro level policy spread, to segregation and marginalisation from mainstream society. Therefore one can infer that a lack of a conceptual and political

lobby has led to a confused delivery of service and this situation has affected policy-makers who designed the ICDS policy.

From the review, we gauge that policy-making is a complex process not fitting into neat tidy compartments. It has been described as messy, fortuitous, random and therefore not open to systematic analysis. While there is little disagreement among policy analysts about the different stages of policy process, there is controversy about how far policy follows a rational and logical procedure from problem identification to evaluation. The appropriate mode of analysis of a policy varies according to each issue and according to the context. This study's focus is on the formulation stage, when issues get identified, defined, and objectives get set; in the policy process when issues can get defined or remain non-defined, in ways thereafter when a policy is translated into action or inaction. The study is not focussed on implementation, as it is not surveying the practice of ICDS all over the country but more on policy formulation issues. The core questions addressed are: How did this policy happen? Who were the individuals or groups behind it? When did it develop? How were the issues identified? How were the goals and objectives defined? And the wider questions of who made the policy? What kind of an environment does the policy function in? What kind of a system and structure contains the policy? The study is essentially a descriptive one; parts of the framework according to Hogwood and Gunn's (1984) typology will be used, giving a 'structured opportunity' to explore issues connected with the policy of the ICDS as well as the larger issue of the disabled children. The actual mechanics of particular techniques and its consequences, the analysis of these particular techniques, is not what the study sets out to do. Analysis will involve determining the characteristics of the issue being analysed, the organisational and political setting of the issue, the description and explanation of the policy and how it was made, the wider system in which it became embedded; the conceptual and analytical framework being set within key theoretical notions, to aid data collection.

PART FOUR

METHODOLOGY

6 METHODOLOGY FOR THE RESEARCH STUDY

Introduction

This Chapter on methodology is in six sections. The first section sets out the aim of the study and the research question; section two the approach to the study and the value of qualitative research; section three details the methodology ; section four the field research done in the community at the local level; the fifth section sets out the research with the policy makers at the national level; the sixth section deals with analyses of data collected.

6.1 The Aim of the Study and the research question

The study aimed to examine how and why the Government of India's ICDS policy was not including disabled pre-schoolers in their programmes all over the country. Although the policy did not explicitly state in policy documents in their definition of 'all children', that disabled children were or were not to be included, we find that they are not included by the ICDS in practice. Looking at the problem in terms of policy, for policy to be put into practice the policy objectives have to be clearly defined. In the real world, some writers argue that, there is 'a blurring of the boundary between policy and practice, and in certain circumstances policies are hidden and can only be identified from practice' (Goacher et al 1986:72). Defining the problem is not simple, nor is it easy clarifying objectives in achieving policy goals. Issues need to get on to the political agenda before they are defined (Dye 1984; Hogwood and Gunn 1987; Walt 1994). We have noted that policy has been described as the work of 'authorities', a 'collective body at the top of the system' who frame the action which

makes it 'easier for some, more difficult for others to take part in the process' (Colebatch 1998:16). Policy-making is an intensely political business with various groups with their vested interests, negotiating, bargaining, and reaching a compromise. The aim of the study was to examine the various stages of the ICDS policy process with particular focus on the areas of policy formulation, issue definition, the definition of objectives and priorities and the way objectives are linked up with practice and implementation. The aim of the study was also to examine the wider implications of this non-inclusion, the socio-cultural value system, the historical and political framework in which this particular policy is embedded. Although on a micro level the research was a study of the policy process through which the ICDS policy emerged, on a wider macro level it investigated the cultural underpinnings, the values allocated to disability, the ideological constraints that lay beneath the system in the Indian environment. The wider objective was to examine the factors which may have influenced policy-makers at the 'top' and at the 'bottom' level, people in the field who are the recipients of policy (Bowe et al 1992).

The Research Question

Bell (1989) writes that it is the research question that dictates methodological approaches to be adopted. The key research question that was investigated with the policy-makers was:

1.What was the explanation for the ICDS practice of not explicitly excluding, but not directly addressing, the needs of the pre-school disabled child within their existing provisions for the weaker and more vulnerable sections of society?

The subsidiary questions were:

a. When was the policy made and by whom? What were the priorities? How did the issue come up on the policy agenda? How was it defined? What and how were the objectives and goals of the programme decided?

b. Who were the people behind policy-making for the disabled? What were their values, beliefs and interests?

2. What is the wider socio-cultural, political and ideological framework within which the ICDS practice exists?

b. What are people's underlying value systems with regard to disability and how are their attitudes affected by their deep-rooted values?

Questions, which were addressed to the community in the focus groups, were:

3. What is the attitude of the family and the community towards their disabled child?

a. What are the factors that inhibit parents from taking their child to the local anganwadis?

b. What do they feel about their disabled child not enrolling in the anganwadi? What do they feel about their child attending the anganwadi?

Questions that were addressed to the local bureaucrats were:

4. Why do the anganwadis not have any children who are disabled? Why do mothers of disabled children not come for this service?

b. What do you think would be the practical problems if disabled children were included?

Details of questions used for the policymakers, the community and the local bureaucrats are in the Appendices 3, 4 and 5.

6.2 An Approach to the Study: methodological issues: the value of qualitative research

In selecting the methodology for this study, it was necessary to make an appropriate approach to the study from the array of methods available, bearing in mind that it was meant to be an in-depth study. The natural and social sciences are split into two schools of thought. One school of thought feels strongly that the methods of the natural sciences that have brought about excellent results are the only methods that should be applied in the study of human affairs. The other school of thought feels that there is a basic difference in the structure of the social world and the world of nature.

Human behaviour cannot be understood without reference to the meanings and purposes attached by the human actors and their activities (Denzin and Lincoln 1994:106).

Research activities can be categorised as qualitative or quantitative. Denzin and Lincoln (1994) argue that,

Qualitative data provides rich insight into human behaviour (Ibid. 1994:106).

Qualitative data is usually in the form of words rather than numbers, concentrating on the beliefs, attitudes and opinions of people, and attempting to describe people's feelings, beliefs and attitudes in their natural settings. The words can be assembled or broken-up into semiotic segments. They can be organised to permit one to contrast, compare, analyse, and bestow patterns upon them, allowing the researcher the flexibility needed (Miles and Huberman 1994). Qualitative research seeks insight rather than statistical analysis. It is more concerned with understanding the individual's perception of the world (Bell 1989). It tends to have a natural setting, researchers spending considerable time in a neighbourhood, with families, in schools and other locales to learn about their subject. The researchers are concerned with process rather than the outcome. How people negotiate meanings? How certain labels are applied? How certain notions become 'common sense' experiences, problems, backgrounds are valuable to understand as they indicate meaning and reveal the culture and the meaning people attribute to events (Bogdan and Biken 1992). Theory

development emerges from the bottom and many disparate pieces of data are interconnected, and the process has been called 'grounded theory' (Glaser and Strauss 1967).

6.3 Nature of Qualitative Data

Qualitative research involves the use of a variety of empirical tools - such as case study, personal experience, interview, observational, interactional and visual texts that describe routine and problematic moments and meanings in people's lives. The data consists of words based on interviews, or content analysis of documents or observation of the phenomenon in question. The data collection activities are typically carried out in close proximity to a local setting for a sustained period. The terms ethnography, field methods, qualitative inquiry, participant observation, case study, naturalistic inquiry, unstructured and semi-structured interviews, focus groups, and documentation analysis have become practically synonymous with qualitative research (Miles and Huberman 1994). Qualitative researchers therefore tend to deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand. Using multiple methods is what doing qualitative research is about. Denzin (1994) calls it a *bricolage*, which according to him is a 'pieced-together close knit set of practices that provide solutions to a problem in a concrete situation'. The result of piecing-together is a *bricolage* and the researcher a *bricoleur*. A bricoleur according to Denzin is supposed to understand that research is an interactive process shaped by his or her personal history, biography, which is an intensely self-reflective and introspective experience. Every researcher speaks from within a distinct community, gender, social, class race and ethnicity and this shapes the process of inquiry making research a multicultural process' (Denzin 1994:2).

However 'deep dark questions about qualitative research remain' (Miles and Huberman 1994:2). The weaknesses of qualitative research are researcher bias, the reliability and validity of data collection techniques, ethical constructs and the difficulties of relating micro-macro theories. However, these weaknesses can also apply to quantitative research. Again in qualitative research, methods of analyses may not be well-formulated whereas,

... for quantitative data there are clear conventions a researcher can use, in qualitative research often, the analyst is faced with a bank of qualitative data and has very few guidelines for protection against self delusions (Miles and Huberman 1994:2).

The craft of qualitative analysis has advanced and matrix and network displays are now common. A more systematic and explicit laying out of the methods used, of the analyses done, to arrive at conclusions has become a means of establishing credibility and reliability (Miles and Huberman 1994:2). Vulliamy et al (1990) writing about research done in developing countries describes that

Qualitative research strategies referring to a broad approach, encompassing different blends have considerable potential for contributing to the study of processes, and divergence between policy and practice by providing analyses which are strongly related to the cultural context and in identifying appropriate questions (Vulliamy 1990:25).

Investigating government policy and the value system underpinning the culture can be sensitive issues. We have noted that decision-making as well as non-decision making can happen in policy, so that policy can be action or inaction (Lukes 1974; Bachrach and Baratz 1977). Since one of the wider aims of the study was to examine the philosophical underpinnings that shape Indian society, the values and beliefs that dictate or influence thinking; it was important to know the underlying attitudes and feelings towards disability, and whether this had any influence on the decision-making of the policy-maker. This kind of investigation needed a sensitive and subtle form of enquiry, such as that offered by qualitative research methodology.

The study is within an interpretative framework, with people as participants and with an exploratory and descriptive focus, My own experience of work in India and in Dharavi, suggested that a qualitative approach utilising various data collection techniques would be most appropriate for the investigation of the research question and in doing so, I drew upon different research traditions as outlined below.

6.4 A Combination of methodologies for the Study

A combination of desk research and field research was done; desk research involving analysis of relevant documents, field research involving observation and exploration of the research site, focus group, semi structured interviews, home visits and triangulations. The areas studied were: the ICDS policy and practice in Dharavi; the community in Dharavi, the family, the neighbours, the local bureaucrats, the environment in which the child lives; the attitude of the community towards disability. This was done through observation, focus groups (Krueger 1994) and triangulations (Denzin and Lincoln 1994); the analysis of documentation (Denzin and Lincoln 1994); semi-structured interviews with policy makers (Cohen and Manion 1994).

6.4 (a) Community:

(i) Observation and exploratory field visits

I began with the field research in Dharavi and initially spent several hours. People were used to me as they had seen me over the years. I was keen to get a holistic view of the ICDS policy and practice in action: its logic, its arrangements, and its explicit and implicit rules. I hoped to get some insight into this through several visits. I visited a few of the anganwadis and noticed the absence of disabled children. I observed the environment in which the disabled child and the family and others lived, in congested overcrowded surroundings, with very little privacy, and yet the community had a great amount of resilience in carrying on such an existence. I asked two community workers to visit the anganwadis. The idea of the observation being done by two others who were a part of the community (in that they also lived in Dharavi) rather than by the researcher was to find out whether admitting or not admitting disabled children was a general practice (Details about the Observation Schedule of the Anganwadis is attached in Appendix 7)

(ii) Focus Groups

In a culture like India where there is a reluctance to answer questions openly, a group situation may help develop openness. Interviewers can sometimes provide rich data in the relaxed chatty format of focus groups (Krueger 1994). The results of focus group discussions are not presented in complicated statistical charts but rather in lay terminology, probably interspersed with quotations from the participants. This was a reason I chose focus groups for gaining insight in studying the community's attitudes to disability. Another reason for this choice is that the hallmark of focus groups is the explicit use of 'group interaction' to produce data and insights that would be less accessible without the interaction (Krueger 1994). Krueger (1994) argues that focus groups 'tap into human tendencies, attitudes and perceptions' and is developed in part by interaction with other people. Epstein (1988) writes that focus groups are particularly relevant to an Indian situation and that they facilitate the identification of specifically relevant cultural features among target populations (Epstein 1988).

In the community in Dharavi, it was important to introduce a degree of informality. The focus groups allowed a small group of people (in this case 5 to 6) to be selected. Criteria for selection are detailed in the following sections. They allowed a flexibility to explore unanticipated issues, which might not have been possible within a more structured questioning situation. It allowed them to come together, examine, and explore certain beliefs and attitudes, encouraging free-flowing discussions within the natural habitat of the community. The discussions enabled one to develop certain themes and sub-themes around which some questions were designed for the semi-structured interviews that followed. I realised that focus groups were not a panacea or the only way to gather the data for the project, therefore triangulations were added through home visits and interviews.

The disadvantages of the focus group as a tool is that, because the researcher controls the discussions, one is never sure how natural the interactions are. If the topic of interest demanded relatively uncontaminated statements of the research participants' experience and perspectives, then participant observation was the closest approximation to this degree of naturalness (Krueger 1994). This study however, was not an ethnography of the life of the community or the classrooms where the nurseries

were being run. The main idea was to understand the community's attitudes to the disabled child, their views about the non-inclusion and inclusion of their disabled children into the anganwadis. Therefore, encouraging discussions around the subject, followed by interviews at home was felt to be an appropriate method of enquiry in getting this information.

(iii) Triangulation:

It has been suggested that exclusive reliance on one method may bias one's understanding (Cohen and Manion 1985) of the area one is studying and therefore 'triangulation' was introduced. The use of multiple methods or the multi-method approach as it is sometimes called contrasts with the generally more vulnerable single method approach (Cohen and Manion 1985:269). Many studies are culture-bound, as was this one. There is in this culture what is known as the 'courtesy culture' (Bulmer 1983) a kind of reticence and fear to come out with the real issues and therefore, out of courtesy, agreeing with issues. The actors may give a response not quite consistent with what they really felt to the researcher. Knowing of the researcher's own work with disabled children, they may give an answer that they presume the researcher might want to hear. They may perhaps not be open about their family's attitude towards their disabled child. Denzin (1990) who has written extensively about triangulations extends his typology to six kinds. I used the one he calls 'investigator triangulation', which uses more than one observer (Cohen and Manion on Denzin's triangulation 1990:256). The triangulations were carried out through home visits, by a separate team of community workers who were trained by the researcher, in the shacks, over a cup of tea as such interaction could not be recreated in focus group meetings and yet it was necessary to ensure validity.

6.4 (b) Historical analysis of documentation

To understand why the practice in the field had not included the disabled child relevant historical records were analysed. It has been argued that,

Current problems are understandable only
on the basis of their past history, giving us
a greater insight into the nature of man, a

sense of human values and a greater understanding of our culture and of the role the social sciences are to play in the progress of society (Mouly 1978:158).

Citing the linguist Saussure, Denzin and Lincoln (1994) suggest that texts can be analysed as parts of 'webs or systems of signification; they can be seen as a set of language systems' (Denzin and Lincoln 1994:315) and because language systems are characteristic of an era (place, class or situation) one can analyse any particular text in relationship to other texts as part of a structure of meaning. Indeed the analyst's or researcher's task, they argue, is to elucidate that structure.

Written history both reflects and creates relations of power. Its standards of inclusion and exclusion, measure of importance, and rules of evaluation are not objective criteria but politically produced conventions. What we know of history is the result of past politics (Scott 1989 cited by Denzin and Lincoln 1994:317).

This was again relevant to the 'backward mapping' (Elmore 1980) the study was involved in. The crucial issue was to obtain reliable and dependable data to validate the sources, and interpret the overall significance based on verifiable data. One way to check on sources was to see if they were frequently cited. Reference books facilitated this task, as did the interviews with the policy-makers. The collection of historical data for the study involved digging into the archival sections of Parliament and into the national and international libraries, as well as the Government departments. It was important to have had access to the archival libraries of the Indian High Commission and School of Oriental and African Studies, The Institute of Education and the London School of Economics provided excellent resources.

6.4 (c) *Semi-structured interviews*

Semi-structured interviews were another research instrument, which was used. Interviews are supposed to allow for a greater depth, flexibility and adaptability than is the case with other methods of data collection, but this depends on the type of interview (Mouly 1978; Bell 1989; Marshall and Rossman 1989; Cohen and Manion

1994). Cohen and Manion (1994) write about four kinds of interviews that can be used as research tools: the structured, the semi-structured, the non-directive interview and the focussed interview. The structured interview is one where the content and procedures are organised in advance and is characterised by being a closed situation. In contrast is the semi-structured interview which is an open situation, having greater freedom and flexibility. The non-directive interview is normally used for psychiatric and therapeutic interviews and the main feature is that it has minimal direction or control. Semi-structured interviews seemed to be more appropriate to get a broader view of the subject. Typically qualitative in-depth interviews are much more like conversations than structured interviews and a useful way to get large amounts of data quickly. The most important aspect of the interviewer's approach concerns 'conveying the idea that the participants information is acceptable and valuable' (Marshall and Rossman 1989:82) Again there are advantages as well as disadvantages in using the interview tool as a research method. The principal advantage is its adaptability, in contrast to the questionnaire.

It allows one to follow-up leads and thus obtains more data and greater clarity, usually permitting more depth than the other methods (Cohen and Manion 1994:307-317).

The interview situation makes it possible for the interviewer to decide which questions are more appropriate.

It assumes that no fixed sequence of questions is suitable to all respondents, and allows respondents to raise important issues that may not be included in the schedule (Denzin 1970:125).

Persons unable to read or write could still answer questions that would be relevant for the empirical research in the community. The interviewer can assess non-verbal behaviour and spontaneity is maintained.

Hammersley and Atkinson (1983) point out that the disadvantages are that it is somewhat naive to say that open-ended questioning is not in itself a kind of social control that shapes what people say. When the researcher maintains a minimal

presence, asking very few questions, this can create an interpretative problem for the interviewee about what is relevant. The interview could be misunderstood and recorded in a subjective and biased manner that could produce inconsistencies and inaccuracies. A serious criticism is that the researcher could be highly subjective, shallow, failing to probe deeply enough and failing to provide a true picture of opinions and feelings. The disadvantages also are that being free flowing and semi structured interviews are lengthy and time consuming. Therefore, it has been suggested that all possible controls and safeguards should be employed for unbiased reasonably objective data to emerge (Bailey 1982; Cohen and Manion 1985; Bell 1989). The combination of methodologies used for the study is given overleaf in a summary.

Table 1: A Summary of the Methodology

Research Question	Key issues of Investigation	Key Informants	Methods used
What is the wider socio-cultural, political and ideological framework within which the ICDS practice exists?	(A) Ideological issues, socio-cultural attitudes underpinning society:	Policy-makers. ICDS Bureaucrats: i.e. Anganwadi workers and Supervisors. Community Family.	Semi-structured interviews; Focus groups Focus Groups. Triangulations
What was the explanation for the ICDS not explicitly excluding, but not directly addressing, the needs of the pre-school disabled child within their existing provisions?	(B) Historical issues: the historical documentation of the ICDS during the time of formulation as well as the Ministries of Welfare and Education.	National archival sections of libraries in London, Bombay and New Delhi. Libraries of Government departments, Planning Commission Policy-makers	Analysis Of documentation and policy records. Semi-structured interviews.
Who were the people behind policy-making for the disabled? What were their values, beliefs and interests?	(C) Political issues: underpinning policy and practice.	Civil servants Administrators Professionals 'Street Level bureaucrats' i.e. Anganwadi workers, supervisors.	Semi structured interviews Semi structured interviews Semi structured interviews. Focus groups Focus groups

6.5 The Data Collection

The empirical work was carried out in two phases, from July 1995 to September 1996 and from January 1997 to April 1997, in all a time of eighteen months. In observing what could be happening on the field level, I investigated the community in Dharavi. In terms of the broader aspects of the research question of why the ICDS had not included the pre-school disabled child during the planning stages, I had to understand the values and beliefs that policymakers attributed to people with disability, the kind of issues they felt might have been impediments to formulating and implementing policy. This was carried out in Delhi. Historical documentation, Government of India records, the ICDS records were accessed from the Government of India and ICDS

offices in Delhi and the Libraries in India and London and the archives of the Indian High Commission, London.

(i) The Whole Sample

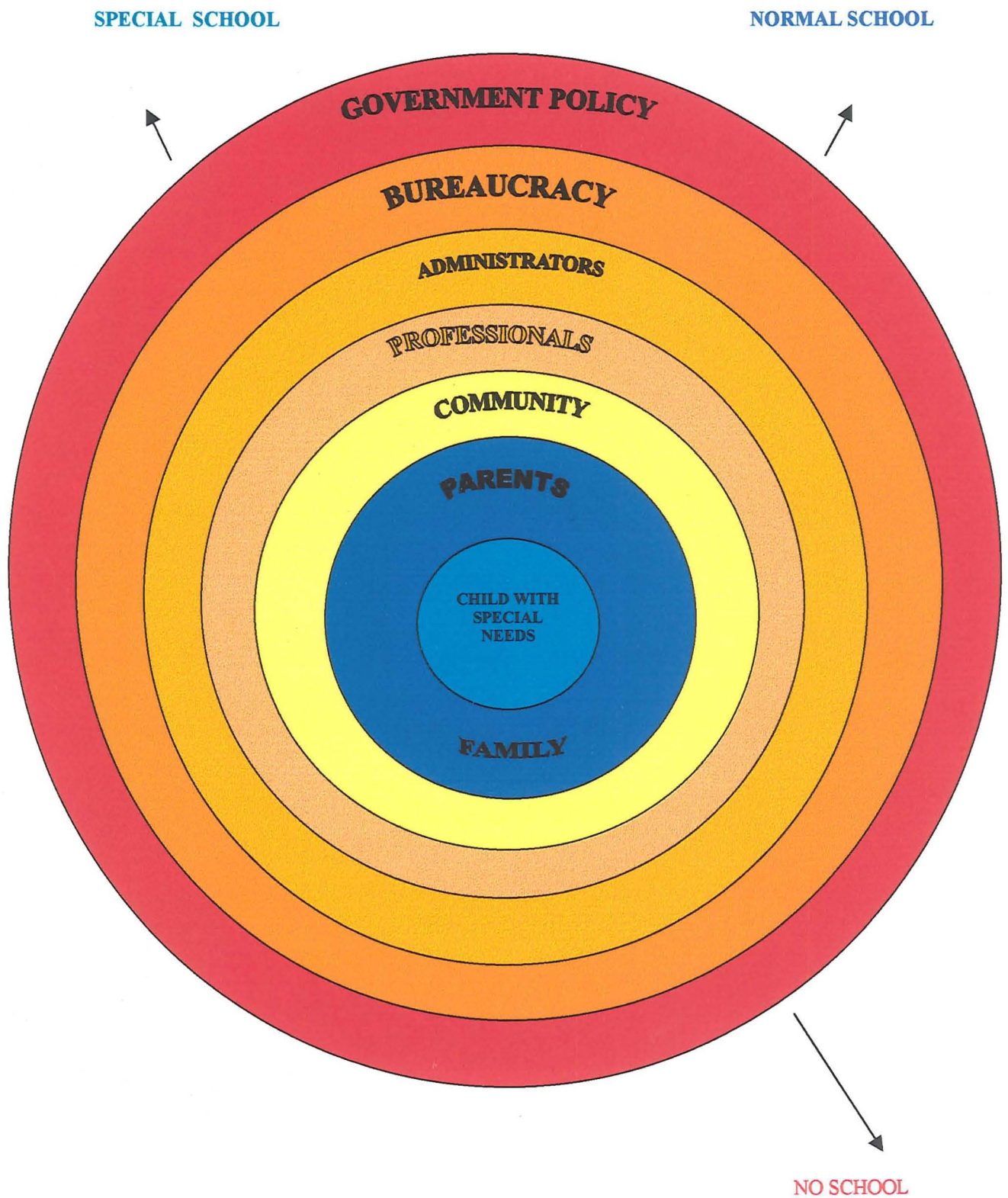
The whole sample indicating different segments under study is shown in a graphic form in Figure 3 overleaf entitled, 'A diagrammatic matrix of the research sample indicating the levels of areas to be investigated within the options available for the disabled child.' The diagram indicates the different segments from the top and bottom of the sample population that was studied. The outer layers show the wider question of policy formulation and implementation that was examined involving the sample of Government bureaucrats, civil servants, administrators, professionals on top: the next few layers narrow into the community, the family, surrounding the child within the environment in the bottom level.

6.6 Community Research in Dharavi

(i) Site for the research

Dharavi was the site for the research. Dharavi was selected for various reasons. It is Asia's largest slum. Fifty-seven percent of the ICDS projects were in city slums. Although the slums would differ in the various parts of the country, this would not detract from the fact that the poorer sections of society lived in the slums, and that there would be common problems in terms of demographic features concerning housing, employment opportunities, literacy and poverty levels (Roy 1995). ICDS operated here in Dharavi, as in other parts of the country, targeting the weaker and vulnerable sections of society. The slum phenomenon was essentially one of rural-urban migration. The difficulties of such studies are several: the constant movement of people going back to their villages, resulting in losing one's sample; the lack of proper records; people who would be available for at least a year. No study can be done in a vacuum. The study needed a well-established base with records of parents living in the area and having contact with the ICDS. The Spastics Society provided this base. It had run schools and clinics here for several years and was in close touch

Figure 3: A diagrammatic matrix of the research sample indicating the levels of areas to be investigated within the options available for the disabled child



with the ICDS administrators as well as others in the field. Therefore Dharavi met the criteria as an appropriate research site for this study.

(ii) Data Collection

Data was collected by the following methods:

- Direct observation: a diary maintained.
- Observation of the local nurseries or anganwadis (Schedule attached Appendix 7).
- Pilot runs.
- Focus group discussions with parents and the community.
- Focus group discussions with staff of ICDS services.
- Triangulations done through home visits and semi-structured interviews.

Observations

As indicated earlier, some time was spent in visiting the slums interacting with the families in their homes in an informal manner. It was an intense contact with the field, maintained over several visits, each of four to five hours duration. A diary was maintained noting details of exploratory visits done and was used as resource base for data informally jotted down. This helped to maintain some documentary evidence of the visits made. Six visits were made to the local anganwadis to re-confirm what we had observed over the years about the issue of non-inclusion of disabled children.

Pilot runs:

All formal texts on research methods mention the desirability of a pilot study and the fact that this is one way in which a research instrument can be honed to its particular task (Johnson 1994:43). Once familiarity with us was established, I planned a few

pilot runs or pre-focus groups. The idea was to use a small number of exploratory focus group discussions in the very early stages of the research, to build up the interview questions and to ensure that the participants' perspectives were being understood. The idea was also to run these pilot test of procedures under varying conditions, to develop a protocol to administer the technique of focus groups (Krueger 1994), as well as help the researcher to get in tune with the respondents in the community. From these pre-pilots it emerged that it would be difficult to conduct the focus groups and take notes simultaneously. Note taking stopped the interviewer from listening from time to time, putting a halt in the flow of thoughts at critical moments when the respondents were talking about their problems. It was decided therefore to tape record the focus groups, but have a colleague from the Spastics Society to also take notes in case certain interactions in body language were missed out. The second lesson learnt from the pre-focus groups was of a cultural nature. In a situation where there could be a language problem one needed to be much better prepared than the researcher was in the language of the pre-focus tests, which was Hindi, to avoid having to hunt around for the correct expressions in Hindi. The third lesson was the planning of the time needed. It was not possible to foresee exactly the length of time that was going to be needed before one could get the group responding to areas that were sensitive.

Certain themes and sub-themes important to the group emerged from these pilot runs leading to the development of a few questions around these themes. These were later used for the focus group. Questions that were designed on the basis of the pre-focus group pilot runs are in the Appendix 3. The themes, which emerged, are given below. The questions had to be translated into two languages of Marathi and Hindi, the languages used during the research on the ground level and most commonly spoken or understood in Dharavi.

Theme A: Facilities existing in areas of health, nutrition, pre-school: Had the local anganwadi included their disabled child? If not in their opinion what were the reasons for the non- inclusion? Would the disabled child benefit from going to the local Anganwadi? What kind of facilities would be beneficial.

Theme B: Difficulties encountered, if any, with accessing State Provisions: difficulties within the community and within the family.

Theme C: Attitudes to the disabled child and family: The reactions of spouse, in-laws, other relatives within the joint family culture, the immediate neighbours and the community.

The three main issues for discussion on the focus group agenda were going to be 1. Facilities existing. 2. Difficulties. 3. Attitudes.

6.7 The Focus Group Discussions

The researcher was now eager to begin the focus groups and felt that she was ready. She was joined by two of colleague who were by now trained to listen, to observe and to take notes. Six focus groups discussions were run. The sample included the community of parents and their neighbours and the local administrators of the ICDS policy known as the anganwadi worker and the supervisor.

The Sample for Focus Groups

The first step was to define the population to be covered and to narrow down on the target population. In the first sample of parents, the catchment population consisted solely of the families of the 'under fives'. A stratified random sample was done based on the Spastics Society's Clinic and the Sion Hospital registers. Stratification was carried out according to age and disability, and it was restricted to parents who would not be moving. The difficulty in such a migratory population is to get the sample constancy needed for the triangulations. Therefore families were selected who had disabled children under five, and who would not be moving out of Dharavi in the next year and a half.

It is important to remember that the type and degree of handicap was not the important factor here, as the study was examining what the families were going through as far as community attitudes to disabled children were and their reactions to the non-inclusion of their children in the local nurseries. Therefore since the base was

the Spastics Society's clinic which had extensive contacts with under-five children with cerebral palsy and other physical disabilities like polio, it was possible to narrow down the target population and choice of a sample which would ensure a constancy with the families remaining in the slums for a period of one and half year. Having got the sample the researcher then grouped them and made out a time-table with the families for running the focus groups. Fathers and mothers were met separately, as in this cultural context mothers rarely talked in the presence of their husbands, especially for some of the sensitive questions asked about difficulties with family members.

The next sample, were the neighbours of families having a disabled child, their selection, kept the children in cohorts, which was pertinent to the study of integration. The total selected number of parents of disabled children and parents of the able bodied and their neighbours was 30.

The discussions were carried out in the local Sion Hospital premises. The people in Dharavi do not get many opportunities to socialise. We all sat on a mat on the floor. Two of my colleagues who spoke Hindi as well as Marathi were with me, so if there were a slight hesitation in understanding my Hindi, one of the moderators would explain in Marathi. This was infrequent, as I had now trained myself for the discussions. As the moderator, I told the group about the study. Permission was taken from the group to tape-record the interview. All participants had agreed. Most of the participants were very articulate and enthusiastic about sharing their views and experiences. A colleague was involved in handling the tape recorder, so that there were no interruptions when tapes had to be changed. The details of the discussions are in Appendix 6. The following focus groups were run:

Focus Group: A (i) was mothers of disabled under fives attending the Spastics Society Clinics; ten in number.

Focus Group: A (ii) was fathers of disabled under fives; ten in number.

Focus Group: B was neighbours of disabled under fives; ten in number.

Focus group discussions with the local administrators of the ICDS programme were also done. This included the supervisors and the anganwadi workers. This Group was denoted Group C. The sample of Group C was selected from the Hospital list where they operated. The Chief supervisor did the selection of the supervisor and the anganwadi workers. The sample of the supervisors consisted of trained nurses and graduates; the anganwadi workers were girls who had studied till Class 9 or 10. They were told of the research and were interested in participating. The Focus Group discussions were carried out in the Spastics Society clinic, which was on the next floor from where the supervisors functioned.

6.8 Triangulations through Home Visits

Triangulations were done through semi-structured interviews carried out by community workers. The sample consisted of one group of families that had earlier attended the focus group discussions and another group who had no services at all. The names of the parents were obtained from the parents and the community in Dharavi who directed us to them. Selection was stratified, as in the focus group discussions age wise to under five, disability wise to children with cerebral palsy and other physical handicaps like polio. The main objective of triangulation was to ascertain the kind of attitudes that prevailed in the community and within the family, and what the parents and the neighbours felt about disability and about including disabled children in the local nurseries or anganwadis. The two groups of Group D were (i) and (ii). The two groups were:

Group D: (i) Parents of able-bodied under fives who had attended the earlier focus groups with the writer; ten in number.

Group D: (ii) Parents of disabled under fives not attending any service; ten in number.

The total selected numbers of parents were 20. The reason for it being 10 less than the focus groups were that these were semi-structured interviews with home visits and 20 respondents was felt to be enough for a qualitative research study and for the purpose of the information that was being validated.

(i) Criterion of selection of the investigators

The investigating team consisted of two social workers, who were not residents of Dharavi, and two community auxilliary nurses who were residents of Dharavi but had never done home visits and were not identified as part of the SSI (Spastics Society of India). This avoided potential undesirable effects of bias due to familiarity. Three meetings were held getting them appropriately trained for the triangulations. The questions and the objectives of the research study were explained to them. A role-play situation was enacted where some of us were the parents and some investigators, to familiarise them with the subject and introduce tactics of gentle probing. The tools for data collection were semi-structured interviews. The advantage of using two distinct groups of people was that inter-observer reliability was maintained. The triangulations reinforced the fact that the collected data had no bias from long-standing familiarity between the observers and the subjects. The interviews were conducted in their homes. The discussions were carried on the floor on a mat (or a satranj). The triangulations showed the mothers opened up much more in this area with the community workers in the privacy of their homes. It also showed that those who did not have access to any services had faulty perceptions about their child with disability compared to the others. This is detailed in the findings. Analysing the findings indicated that this was a successful methodology to add to the research design. However although parts of the interview indicated that the families opened up more with the home visits, it was not a significant amount. The focus groups gave the community research a strong database with more controls in place, which was not achieved with the triangulations where the writer had to depend on others and their judgement. However, for the sake of reliability and to ensure that there was no bias with participants modifying or even reversing their positions after interacting with others, triangulations through home visits were useful. I was able to check and counter-check findings. Several meetings and discussions with the community workers on the findings allowed me to validate the data collected. The tape recording of the focus group discussions allowed me to play the tapes frequently to be sure of the information gathered.

6.9 The policy-makers' perspective

(i) Data Collection

The interviews with policy-makers, academics and professionals took place in New Delhi, from where policies emerge. Data was collected through semi-structured interviews. Each interview lasted for approximately an hour and a half.

(ii) The Sample

The number of participants was 25. The study being exploratory and open ended, the selection required the researcher to delineate precisely the relevant population or phenomenon for investigation based on theoretical and conceptual considerations. The traditions set out by Goetz and Le Compte (1984) called criterion-based selection was followed.

Criterion based selection requires that the researcher establishes in advance a set of criteria or list of attributes that the units for study would possess (Goetz and Le Compte 1984:73).

Simple criterion based selection requires that the researcher creates a recipe of the attributes essential to the selected unit that matches the recipe (Goetz and Le Compte 1984:77).

People selected were important people in the Government and some directly associated with the ICDS policy: people handling policy formulation and implementation related to the education of able bodied children and disabled children. Besides the bureaucrats and administrators, it also included professionals, academics and researchers in the field. They were also senior people in the Government all of the level of Joint Secretary¹⁸ upwards. Therefore the kind of agencies or organisations they represent, the kind of thinking they represented and the positions they held, were the criteria used to determine the selection (See Appendix 9 for more details about the sample).

¹⁸ A Joint Secretary in the Government of India is third in rung of seniority in the civil service.

(iii) The Interview schedule.

To get the best out of the semi-structured interview as a research instrument it has been suggested that one needs a schedule. Cohen and Manion (1994) write that it involves translating the research objectives into the questions that would make up the main body of the schedule. Once the variables to be measured have been identified, questions should be designed to reflect them (Cohen and Manion 1994:321). Open-ended questions using a language familiar to the respondent usually obtains a higher level of reasons rather than questions, which require short answers (Mouly 1978). Questions should be tailored to probe avenues of exploration that will yield information relevant for the hypothesis. There should be flexibility in terms of questions asked (Bailey 1982:182).

A language familiar to the respondent had to be used, which for the policy makers was English. Assuring respondents of confidentiality of any comments they would like to make about certain issues increased their willingness to answer questions that might be perceived as threatening. Most of the interviews were carried out in the offices where people worked. They were mostly uninterrupted.

(iv) Tape recorder

Taping the interview rather than note taking has been suggested by social scientists as a means of avoiding bias (Borg and Gall 1989; Silverman 1995). The advantage of the tape recording was that it could be played back several times going over critical areas. The verbal interactions which took place could be studied much more thoroughly than if data were limited to note taking. The possibility of reanalysing the data by another person other than by the interviewer makes it possible to check the reliability of interpretations.

The advantage of the tape-recorder is to reduce the tendency of the interviewers to make an unconscious selection of data favouring their biases (Borg and Gall 1989:444).

Permission had been obtained in the earlier letter about the tape recorder but I mentioned it again at the beginning of the interview to make sure that the interviewee

did not object. Nobody did. An interview checklist of interviewer details had also been prepared and at the end of the interview this was duly signed by the interviewee for the record.

A study and analysis of Government of India (National and State) documents and policy related to disability, pre-school provisions and ICDS policy was also done. The collection of data involved digging into the archival sections of international and national libraries, as well as Government departments. The documents that were analysed are cited in the Bibliography under Government of India sources. The informants at the top level did refer to some of these documents which re-assured me that the material was authentic and reliable.

6.10 Analysis

It has been written that there is no one kind of data analysis but a variety of approaches related to the different perspectives and purposes of social scientists. Despite the differences in approach and language, the common emphasis is on how to categorise data, and make connections between bits of data and segments or units of meaning called categories. These tasks constitute the core of qualitative analysis (Miles and Huberman 1994; Goetz and Le Compte 1984; Silverman 1994).

The community research

The focus groups were in two vernacular languages and the material was transcribed and translated into English by a colleague of the researcher, one who had earlier participated in the discussions. Each focus group had produced 10-12 pages of notes; altogether there were 50 to 70 pages of transcribed notes. A critical aspect in surviving the deluge of data was to focus the analysis. Not all questions deserve analysis at the same level. Some may be 'throw away' questions that were designed to help set the stage of discussion for participants as opposed to gaining new insight. Others are key questions representing areas of primary concern constituting the backbone of the research. Focussed analysis enabled one to concentrate attention on areas of critical concern (Krueger 1994). Coding and analysis was done according to

the themes and sub-themes that emerged after the focus group discussions. Colour Coding was used for identifying the certain categories within the themes and sub-themes. Category development required a thorough familiarity with the data, which the researcher now began to acquire. Next an attempt was made to categorise and sub-categorise them into groups and clusters bringing the data into a sort of structure and order (Goetz and Le Compte 1984; Miles and Huberman 1994). The data analysis took shape. Linkages could now be seen. The next step was to compare, group and contrast the categories and subcategories as suggested by Goetz and Le Compte (1984) establishing these linkages and relationships. Analysis also involved study of reliability and accuracy of answers through cross-checking findings.

The interviews

The semi-structured interviews created a sea of data in the form of 75,000 words! The initial reaction in confronting this sea of words, in which one tends to get submerged in, was sheer panic. There were two major factors that helped me. The first task was of transcription. The act of reading and listening slowly and carefully and transcribing them on to the computer, although arduous, was indeed the beginning of getting immersed in the data. The fact that one could play and replay the information several times was another very useful means of familiarising oneself with the data.

The second task was analysing the data through a computer software programme known as the Nud.ist. Nud.ist stands for Non-Numerical Unstructured Data Indexing Searching and Theorising. Once the raw data was transcribed, it was possible to convert this into the Nud.ist Power Version. The Nud.ist programme permitted organisation of this immense amount of material, exploring the complex unstructured data, in a matter of seconds. The entire 75,000 words were now retrievable in manageable text units collated to 3,500 text units. To explore the data several times making categories and subcategories required a consistency and skill that the software facilitated. The time taken was significant because the computer organised text units in a matter of seconds. It could verify references to any data for interpretation and analysis. It could link up, correlate and help in developing patterns and scrutinise the data through a systematic rigour. Although time consuming and arduous, it was an

invaluable and an exciting tool in analysing 75,000 words. (More details are in Chapter 8).

(i) Inter-rater reliability

Verifying one's own thinking in the analytic process against two others was important to get a degree of rigour into the analysis. To test reliability of the categories and subcategories that I analysed through the texts, samples of texts were handed to two analysts, both of whom in this case were the researcher's supervisors. The analysts described as 'raters' by writers of qualitative research methodology (Silverman 1995: 148) analysed the text with the list of categories and subcategories that had been developed by the researcher. This was followed by a discussion and differences occurring in each person's analysis were ironed out, an activity which took time, but one which was critical if inter-rater reliability (Silverman 1995) was to be checked before moving on to final coding.

(ii) Inter-researcher

A second test of reliability was the inter-departmental research workshops which were held, where several fellow researchers were asked to give excerpts of their research analysis; after the researcher's rendition of events the text analysis were 'deconstructed' (Clough 1992). This was a good way of exposing one's biases and taken-for-granted notions with one's fellow researchers giving ideas of some alternate ways of looking at the work introduced.

(iii) Inter-public

Another way to test out some of the study's findings was by exposing the findings to a larger domain. The researcher wrote in the national newspaper and read a paper at a series of national conferences on 'Segregation or Integration' in India in three cities, where the audience was made up of Government officials and professionals in the field of education and special education. Again this was a means of verifying whether any of the facts obtained pertaining to the history and the analysis of policy formulation and implementation were in any way off the mark. This did not seem to

be the case; and what was interesting was that most of the audience felt that disabled children should have remained with the Ministry of Education.

Summary

The chapter described the aims of the study, the research question and the approach to the study. It explored briefly the methodological issues of quantitative and qualitative research, and argued that such a study investigating sensitive issues needed a qualitative rather than a quantitative approach within an interpretive framework. The choice of research designs and methods involving a combination of methodology was discussed as also were the advantages and constraints. The research design describing the data collection for the empirical research was set out, and details of research tools provided, moving on to the analysis that had two different approaches for the community and the policymaker. Various analytical strategies to reduce bias and ensure reliability were also described.

PART FIVE

THE EMPIRICAL FRAMEWORK

7

DHARAVI

Introduction

Chapter 7 details the findings of the data collection done in the community in Dharavi. It gives a bird's eye view into the indigenous mores and beliefs that prevail in the microcosm of a subculture of Dharavi, perhaps improving our understanding of a wider social structure of beliefs and values underpinning the subcontinent. Details of the research tools and analyses have been already addressed in the earlier chapter; data drawn from the focus groups, triangulations, and relevant documents is reported in this chapter (See Appendix 3 for more details).

There has been a great deal written about the proliferation of slums in the metropolitan cities in India and their associated problems, but little or nothing about how it affects the child with disability and the mother within these very difficult surroundings. Attitudes are all pervasive and the values held by people within the social structures can lead to action, which could be discriminating. The study was an attempt to capture data on the perception of the local people living in the community, as well as of the local ICDS bureaucrats who administered the programmes. The investigation was carried out based on the themes that emerged from the pilot runs. The main themes and the sections reporting the findings are detailed below:

- (i) The Facilities and Services that exist;
- (ii) The difficulties encountered;
- (iii) Attitudes of the community to disability and the socio-cultural structure;

- (iv) The ICDS administrators and their perspectives towards the question of the non-inclusion and inclusion of disabled children into the existing programme.
- (v) An analyses of the ICDS documents.
- (vi) The findings.

7.1 Facilities and services existing

This section explores the facilities and services provided by the State as explained by the community. All mothers seem to be availing themselves of the local municipal hospital facilities at Sion (the area within which Dharavi was located). They went to the hospital for their children's immunisations. This was the practice for those who did not attend the anganwadis; for those who did, the anganwadis administered the immunisation. Every child in the group seemed to be having fits: the mothers went to the hospital to get Gardinal (a common drug for stopping epileptic fits). There seemed to have been frequent interaction with the hospital both about their child's fits and during sessions of immunisation. There was even awareness about advanced medical diagnostic methods such as a CT scan, but unfortunately what it was supposed to do was not understood or had not been explained, as one mother was under the impression that it was a method of treatment.

From the focus groups it appears that the families were all aware of the anganwadis or the local nurseries, because the entire group's normal children went there. They did not take their disabled child there, though. Two of the mothers had tried to enrol their disabled children in the same anganwadi, but were told that the service was only for normal children and not for those 'who couldn't walk, talk or indicate their toilet needs'. They were not aware that there was a service called ICDS or which agency provided the service. The Government's Health Department ran the local Municipal Hospitals where the family could go in case of an illness or for the child's immunisation etc. However no specialist services were provided in the way of treatment and management for the disabled child provided by the state. There were a few NGOs that had laid on specialist services. Details of two of the NGOs providing services in Dharavi are in Appendix 8. The specialist services of these NGOs took

care of their children's 'special needs'. Therefore, the question of pressing for the admission of their disabled child into the local anganwadis did not arise. None of the fathers group knew of the ICDS and had no idea where the anganwadis were in their area, or what services were being offered there; one of them knew that there was a midday meal.

The focus groups that were conducted to elicit this information about attitudes prevailing in the community began with the parents giving an introductory preamble about their own child. Being in a group situation had a kind of neutrality, they all seemed to be talking freely, at a certain point of the discussions when talking about the attitudes within the family, mothers became reticent. Questions were framed differently talking not of their problems but of other people they might know, who had disabled children, and what was their experiences in the community and within the family. Conversation flowed freely, as they then related what they had seen and heard in the neighbourhood.

To the question about what were the advantages of disabled children being included in the local anganwadis, the mothers discussed the advantages and disadvantages. Initially they said they would not send their child to the local anganwadi with their siblings.

They were very satisfied with the skilled voluntary organisation staff and the services they received free of cost. They compared their situation and the services provided by the Spastics Society with the anganwadis functioning and they felt that the mothers, teachers and helpers were only attracted to the nutritional supplement provided. Pulses like channa (dry lentils high in protein) and rawa (a wheat preparation) were being given. Channa and rawa are very popular and sold well outside. As the group conversed, they began discussing the advantages, and said they felt that maybe it would be beneficial for their children to attend the anganwadis with their siblings. This group said that often the children got only a small helping and the AW workers sold the rest. They would be able 'to play with normal children, learn from each other, and generally feel good'. They went on to say that maybe the intelligence level of their child would improve if they attended an integrated class. Other benefits that could happen if their child was admitted to the anganwadis were:

He is alone and does not get an opportunity to play. If he went to an anganwadi he will get that chance.

It will make us feel good that our disabled child is also treated like normal children.

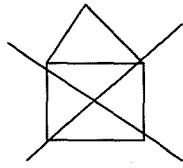
He may strive to achieve something when he sees others.

Anganwadis are close to our homes, if our child is attending, we (a mother speaking) can look in on them in case there is a problem.

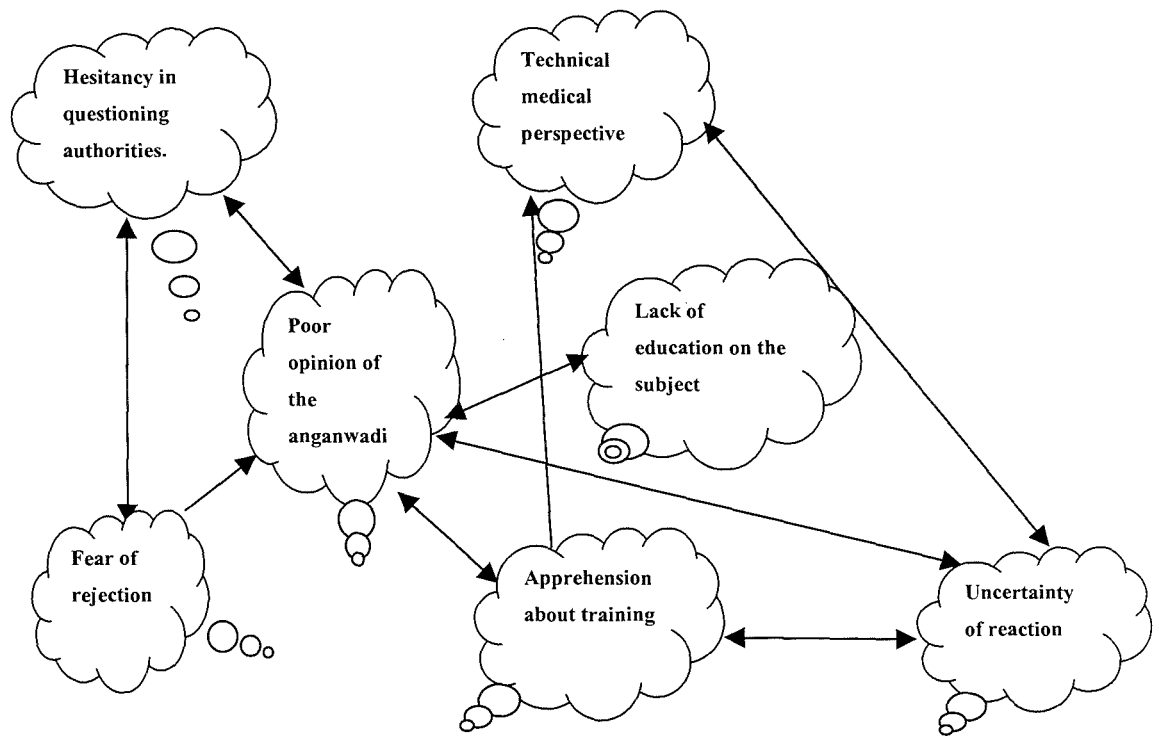
The group felt that the child with disability must be educated so that he or she is not different from any other child. It was the general consensus that their disabled child would find it extremely difficult to attend the anganwadis if no toileting arrangements were made for them. None of the anganwadis have attached toilets children usually have to either attend the communal toilets provided by the municipality or use the open surrounding areas. This lack of sanitation and drainage was an endemic problem in Dharavi. However, if their children were admitted, they offered to take them to the anganwadis, as well as to help toilet them if necessary. The focus group discussion also centred on the anganwadi workers' training. The groups felt that the anganwadi worker needed special training to look after their 'special child'. They were apprehensive about how the anganwadi worker who had not finished school, would handle their child.

The findings of the reasons for not taking their child to the local anganwadi are shown in Figure 4 overleaf.

Figure 4: Reasons mothers gave for not attending the local anganwadi



Non-inclusion into the Anganwadi



KEY:

	Indicates a blur and an ambiguity
	Indicates their suppositions, some of which are inter-related

7.2 Difficulties encountered

To the question about what kind of difficulties parents face in the community, the initial reaction of the group was to deny that any difficulties existed. They just smiled and said there were no difficulties. Later, however with a little probing, practical and basic issues such as toileting and carrying children in buses came up. There being not enough toilets in the slums, parents found it terribly difficult to toilet their disabled child. Communal toilets existed in the slums but no modifications, were allowed without official sanction from the municipality. The families used a simple method of paper in their hutment, which after use is usually thrown away. Again health hazards and a lack of hygiene are permanent features in the slums.

Public transport they said was a big problem as it was usually extremely crowded and irregular. Carrying their child and waiting for hours was very difficult. Parents found it difficult to keep hospital appointments for treatment and therapy or to go visiting relatives. A mother described how she found it almost impossible to carry her five-year old child and described a situation when a co-passenger did not understand why she was carrying such a big boy and asked her what was wrong. He could not understand why she kept losing her balance so frequently, but despite seeing her discomfiture she said he did not give her a seat to sit. Some buses do have seats for the disabled person but often according to the group's experience, an able-bodied person takes this up and the practice goes on without being questioned.

Moving on to other difficulties, a lack of socialisation for the mother and child appeared to be a key issue. Here in Dharavi, there were no parks or playgrounds. Usually the children played outside their shacks in the narrow alleys. When asked if the disabled child played with others, and if they were teased, they felt that at the young age of five and under, there was no discrimination against their child when children played together (although they said often that the child was only an onlooker). It was only as the child grew older that teasing began. The group felt that in general children 'loved each other' and that it was only after being 'coached by adults that they learnt about the difference between normal and disabled'. However, a few of the parents of normal children (the group who were the neighbour to the

families with a disabled child) said that they did not like their children playing with handicapped children because of their children getting infected. As nobody was available to take them out most of the children lay at home for a major part of the day. Understandably, because of the situation they were placed in, there was a lack of social activities for the mothers and their children. Taxis were expensive. Outings were seldom planned. The findings showed that the mother hardly left the house. The inaccessibility of the local buses and the exorbitant taxi fares were beyond the reach of the family in Dharavi. There were no services which brought them together to talk about their common problems. This added to the isolation of the family and the child, making socialising an impossibility.

There was a lack of awareness about what is good practice at home. One parent confessed to the community worker, in the discussion at home, that she tied the child upright to the chair because he could not sit up. The importance of education was considered only in a very remote way. The findings showed the respondents to be fairly constant and stereotypical in their understanding of their child as a medical problem. They had all been to the local hospital. Generally they seemed to think of disability as some disease, which needs a doctor and medicine. There was a heavy reliance on 'medicines for a cure'. One mother said:

Mostly such children are given these tablets only. I don't know the name but if I go to the chemist and ask him for medicine for disabled children he knows what to give and gives me the right medicine.

A large number of doctors seemed to be treating the child with tablets or alternately suggesting 'operations'.¹⁹ The families who were not attending the Spastics Society's clinic talked about the drugs they were being prescribed by doctors at the local Sion hospital. They talked in terms of 'operations' but said that since their child was still young they were not willing to do this, others talked about not having the funds to do it. When asked about other facilities apart from the medical help they received at the local Sion Hospital they were not aware of any other

¹⁹ These accounts were similar to the work in the early days of the Spastics Society too.

facilities. The families were spending a substantial amount of their own earnings on 'treatment' which was generally medicine. The fathers said they did not grudge the expense, but obviously felt strongly enough to bring it up in the discussion.

What was significant between the two groups (the group who received services from the Spastics Society compared to the group receiving no services at all) was that the group not receiving any services doubted the need for anything in the way of education or therapeutic intervention. There was a heavy reliance on 'medicines for a cure' apart from faith healing and the medicines they received from time to time from the doctors in the hospital. In this group there was a total lack of knowledge about their child and its management.

7.3 Attitudes to the disabled child

It was reported that the community was full of pity and most sympathetic about what had happened, but the birth of their handicapped child was generally regarded as a calamity. Neighbours and other members of the community would try and be helpful and come and tell them of people who would be able to 'cure' their child through certain medicines, about gurus and faith healing, of evil spirits being exorcised by witchcraft. A strong fear of disability being infectious prevailed. Instances were quoted when neighbours instructed their children not to eat or drink food that was touched by a disabled child; mothers of able-bodied children instructed their child not to play with the disabled child in case of getting infected. In one case, the normal child was beaten for disobeying his mother and playing with a disabled child. The nature of disability was not understood. The doctor's instructions were misinterpreted and due to inadequate knowledge and lack of time from the doctor's side in explaining what had happened, the following misconceptions prevailed:

- a belief that all malnourished children were assumed to have TB;
- children with congenital deformities were assumed to have leprosy;
- since both TB and leprosy came under infectious diseases which were endemic in the slum,

certain kinds of disability such as cerebral palsy which was difficult to understand compared to sensory disability, was associated with being contagious.

There was also a strong fear of heredity. Some of the couples decided not to have another child because they assumed that maybe the next child would also turn out to be disabled.

The Karmic theory of traditional Hindus, about the present being a reflection of past deeds was strongly entrenched. There was a belief that the family and the disabled child's misery in this life were a result of past life. The neighbours taunted the family whenever there was a quarrel, and brought up the fact that they were cursed because they had a disabled child. Some were told to 'forget' the disabled child and look ahead. Some heard their neighbours saying that:

It is unfortunate that they have a disabled child. It is God's way of punishing them for past sins.

Some day God will forgive them and their child will be normal again.

We do not know why God is putting them through this kind of suffering.

All members of the group felt that this way of thinking was harmful and wrong, and should change. Society only looks on. The family members distance themselves from the community. It was very detrimental both to their child and themselves. What came up strongly was that having a handicapped child was something dreadfully wrong to be 'hidden away', a taboo and a stigma, a result of past sins committed; what also came up was the strong feeling of the group that something should be done to change such a negative attitude to their child.

With regard to difficulties within a family, rejection of the child within the family seems to be most painful. In some families, the mother was supposed to do everything for the child. The mother was the most important person in the child's life and it was most important for the child that the mother accepted her disabled child, because if a mother rejected the child, the community and the entire society would do

so too. Regarding help around their homes, some claimed that fathers did help in taking care of the child, especially in areas of giving medicine and food, but nothing else. This would be in keeping with the culture where the man was not expected to do anything around the house and where looking after children and home was a woman's job. Some complained that, although they were a part of a joint family, the mother-in-law, brother-in-law and husband just sat around and did not help with the disabled child. The general consensus was that all members in the family like mother, father, mother-in-law, father-in-law, sister-in-law, and brother-in-law, husband seemed to be 'in tension if there was a disabled child in the family'. The home interviews carried out by the community workers revealed that there was stress and frequent bickering. It would be hard to say whether this was just because of the presence of handicap in the family or other factors to do with their poverty. Some members of the group did not participate in the discussion. Alcoholism, physical violence in the family, unemployment, was all a common part of their lives. Stories were recounted about fathers who had left the country and remarried leaving the mother to cope with the handicapped child. That mothers-in-law held their daughters-in-law responsible for the birth of their child was a strong finding from the group discussions, as well as from the individual interviews, during the triangulations and home visits. One mother related the story of how her mother-in-law blamed her for the birth of the disabled child, and had convinced her husband to remarry. Some excerpts from their revelations follow:

Whole day she keeps on talking (the living-in-mother-in-law) something or the other, blaming me for the birth, and I have to bear it otherwise its difficult to run the house.

Back in the village she accused the father of the daughter-in-law of lying and getting his daughter married to her son under a falsehood,

You lied and told us your daughter was okay and got your daughter married to my son and now she's got this son.

This tirade was carried on in the village where the father and the mother-in-law happened to live, so all villagers heard about this. The father, whenever he met his

daughter, would actually weep and urge the daughter not to have any more children and to have an operation to get herself sterilised. Her husband refused to give permission for her to do this, as he said 'if she died who would look after the handicapped child?'

The triangulations done by the community workers gave further insight. Most of the neighbours confirmed that the daughter-in-law was accused for what the family saw as a 'disaster of having a handicapped child'. One neighbour recounted what was happening to a neighbouring mother, in her neighbourhood:

She often goes without food, and falls down from exhaustion I guess. We give her tea or something to revive her. The mother rules her husband. She does not want them to be happy. Her sister-in-law also lives with them and is always creating trouble for the daughter-in-law. We cannot do much. Once my husband told the husband about the mother falling while fetching water, the entire family attacked us with all sorts of allegations that my husband had illicit relations with Deepak's mother! (Deepak is the handicapped child). We were all taken aback. We decided never again to interfere but we feel sorry for the woman and her desperation over her child's welfare.

Basically they could do nothing about it. This would be a typical story in a socially backward community anywhere in India. Statements such as '*her husband was ruled by the mother*' or '*her sister-in-law lives with them and creates trouble*' are common socio-cultural patterns especially in the poorer less advanced segments of Indian society. In some families, the husbands left the wife as he said 'she was only capable of producing disabled children' and in some homes the mothers-in-law used it as a weapon against the daughter-in-law. The neighbours and relatives brought it up in any quarrel accusing the mother that she was being punished by God and deserved the child. This, quite often, made the mothers angry and hostile towards the disabled child. One of the mothers tied up the child inside the house so that nobody could see him and accuse her or tease him.

A neighbour remarked,

I pray to God that no one should have a disabled child. It is a torture for the mother of such children. They are blamed for bringing such misfortune in the family.

Cases of extortion were reported and faith healers and extortionists told families that their child would never get better, unless the money was given. Faith in God and faith in healing with oil etc. had been tried out and reported to have failed. Families had to part with their clothes and jewellery in order to pay for the medicine. Belief in quacks led to loss of savings for some. A mother said,

As there's no improvement we will continue to search for the right kind of medication which will cure our daughter.

The persons who extorted the money from them would often not show up again after receiving the amount. The reasons for this kind of shopping around for a proper cure were several and included a prolonged disbelief that their child would remain handicapped for life and a strong desire to correct the situation and make their child right again.²⁰

Fathers indirectly blamed their wives. They defended their mothers and felt that their wives were '*over sensitive to comments*'. Any mother-in-law according to them will blame the daughter-in-law! This was confirmed to be more the norm than the exception. The findings from the fathers group discussions were that '*wives should learn to cope with the taunting remarks and not bother them with their complaints*'. The general feeling was that the entire pattern of living had to be changed to adjust to the needs of the disabled child. One of the mothers in the focus groups said:

People are sympathetic and although they do not reject our company they seem to shrink from it. Neighbours cite our example when they are abusing and fighting or scolding their child.

¹⁵ There were more of such comments from the group that did not attend the local NGO service of the Spastics Society

‘God will make you like Neelam’
(different name of child used).

That is why I feel that people who have disabled children are unfortunate and cursed..

And again,

At times I feel that there should be a miracle and God should cure every disability and remove it from our sight.

Perhaps due to fear, ignorance and a complete lack of services in their lives, some feelings expressed by some of the mothers were:

I have not given up hope. Some day there will be some kind of facilities available for such children and then one-day my daughter will become normal again.

And,

A disabled child’s parent is so overburdened that they cannot enjoy life at all as long as the disabled child is alive.

And,

Parents can never have peace of mind as long as they live.

The group did not see it as anyone else’s problem. It was their personal tragedy. They were not politically conscious of their rights as citizens of the country. Their political weakness seemed apparent in their naivete and simple acceptance of everything around them. It was their personal tragedy. A problem that belonged to a cursed family. They were not aware of anything to do with their own entitlements or needs or the fact that they had a right to have their views represented before the Government in Parliament. They did not know who their elected Members of Parliament or local councillors were. They were also a powerless group dependent for their shelter and survival on the Government. It was not surprising therefore that they accepted their situation without any questions asked.

7.4 ICDS administrators and their perspective towards the question of inclusion of disabled into the existing programme

In the ICDS programme an Anganwadi Worker (AWW) is the most important ‘street level bureaucrat’ (Lipsky 1980) who provides all the services in the project area. The findings from the focus group discussions with them revealed, that the anganwadi workers basically felt that it was not right that they should not include the disabled child, but that they would have enormous difficulties of managing them if they were included. The anganwadi workers said they all had some experience with handicapped children, in that they had seen them around in the slum. They felt that there would be problems for other children if disabled children were included, unless the toileting facilities were worked out. They also felt they needed knowledge and information about the children as their training did not include how to handle children with disability. A major problem of space was brought up. All anganwadis within each locality functioned within the smallest of spaces. Other difficulties that were mentioned:

- No running water.
- Little or no drinking water.
- No toilets.

To the question why the ICDS had not made any effort to secure proper places for the centres, the philosophy of the ICDS was mentioned. The main objective of the ICDS was to provide a courtyard school within easy reach of the families, literally in the backyard of where the community lived, so nobody had to travel far. Mothers were not expected to bring their children to schools, as the helpers did that. The services usually began in a rented place. The rent paid was a small amount. The room given was tiny. Cooking was carried out at the corner of the room.

To the question about their difficulties and why they had not brought this to the notice of the ICDS authorities, they replied that this had been done several times but no communication had been received from the authorities. The problem of space, lack of proper toilets, water are major problems in the slums which have been recorded

substantively by writers and researchers over the years, without much response from the authorities (Roy 1981; De Souza 1978; Singh and Pothan 1982).

The anganwadi group mentioned the difficulties of parents of disabled children and said that mothers did not bring their child because:

Mothers feel that the teacher will not be able to give proper attention to her special child.

Their difficulties were also brought up.

We will not know what to do with them.

Or as mentioned earlier,

It's difficult for us to manage these children without any training.

They felt that if the mothers could help out with the toileting that would help greatly. They also felt that if a small incremental amount were given as an incentive to include disabled children, this would ensure the admission of these children. It is interesting to note that the anganwadi workers were only educated till Class 7 to 10 and yet they were the most overloaded and underpaid of the ICDS hierarchy of bureaucrats.

The focus group discussions with the supervisors of the ICDS took place in the ICDS offices as well as in the Spastics Society's clinics. In different ways the workers said the same thing; that even if the disabled child was admitted, a single teacher in-charge of thirty or more children could not look after the disabled child as he or she would require all her attention and it would take up too much of their time. Almost the entire group said they had encountered at least four or five young children who were disabled round and about them in Dharavi. However they were sure that between 3 to 6 years of age no disabled child attended the ICDS programme.

The reasons given were:

We are not encouraged to do so because they cannot cope with them. ('they' meaning the anganwadi workers).

And

We do not know what to do with them. ('them' meaning disabled children).

Talking about some of the difficulties that they might face if the disabled child were allowed to be admitted, they said that helpers were there to bring the normal child to school, but what would they do for the handicapped child, who would bring them to school, how would they come? Extracts from their responses are noted below:

There is nobody to bring these children to school (it was assumed that the helper could not).

The mother will have to leave the house and bring the child to school, which she finds impossible.

Most mothers are involved in some form of income-generating activity. They therefore would rather keep children at home. They would not have time to drop them to school and some family member will feed and look after them.

Those children who require assistance do not attend school because it is difficult to bring them in and also difficult for the teacher to manage.

Clearly it was assumed that the existing helpers were either 'not available for these children' or 'they would not be able to cope with them'. The Lipsky (1980) theory of the power of the 'street level bureaucrats' finds an interesting relevance here, where the supervisors were able to find a means of justifying their actions in Dharavi according to their own line of thinking. They too had not questioned the practice of non-inclusion but instead had explanations for it.

Another major concern was the lack of toilets. Children usually run out and use the open drains for defecating and they wondered what the disabled child would do. Again they had assumed that every handicapped child would have physical problems. This could be because they were aware about the work of The Spastics Society. The

supervisors mentioned a lack of training and said that since there was no training given to the anganwadi workers they would not be able to handle disabled children.

Their training was available at various districts of Maharashtra (the state in which Dharavi in Bombay is situated) such as Kosbad in Thane, Nagpur, Sholapur, Amravati, Nasik and Dhule. The supervisors were either graduates or trained nurses. There was no specific training on disability. A half-day session was devoted to identification of disability and referral. The response to extra training for the AWWs was that such a question did not arise, since in the 3 to 6 year age group disabled children did not attend school; and since there were no disabled children it was not necessary to have training about how to handle them. To the question whether the workers would be interested in attending a special course if such a course was offered by an NGO, the answer was realistic:

Employed workers will not be able to attend without permission. If the timings are suitable, some might attend a short-term supplementary training. This training could be for two days.

To the question whether they felt that ICDS would take up the integration of children with disabilities into existing services the answer was the following:

We follow the instructions given by the State. If we are asked to do it, we will.

‘If we are asked to do it we will’ indicates an absence of a State directive to include disabled children.

7.5 Document Analysis

Syllabus for Anganwadi training and the syllabus for job training of supervisors of ICDS programme

The syllabus for the supervisors and anganwadis was examined. The syllabus included a half-day time allotted to identification of disability and referrals. As mentioned by the supervisors, areas concerning management of disability were not

included. It is interesting to note that the same kind of courses were conducted by the Ministry of Welfare's training courses for staff training which also had a major thrust on identification and referrals (Appendix 10). The ICDS training included nutrition and health, ensuring child survival and safe motherhood through immunisation, health check-ups and referral services (Appendix 2).

In the area of disability, the details of the syllabus is given below:

- Early identification of disability.
- Prevention of disabilities through immunisation.
- Identification during home-visits and health check-ups.
- Referral of cases to the primary health centres.

(Source: Syllabus for the Sandwich Training of Anganwadi Workers of ICDS Projects - Phase I, II & III, March 1995, NIPCCD).

Research Overview 1975 - 1985

The following extract from a ten-year Research Overview from 1975 to 1985 of the ICDS programmes is given below:

Since 1975-76 government has made intensive efforts to actively implement, improve and expand the programme. ICDS has been subjected to research and evaluation since its inception and is also being monitored to some extent. Many technical institutions, Medical Colleges, Schools of Social Work, Home Science Colleges etc. are involved in conducting research on ICDS. The overview of research gives enough evidence to support the fact that ICDS has produced the desired impact on its beneficiaries and has brought an improvement in some of its most crucial health and nutrition, immunisation, nutritional status morbidity pattern immunisation etc. (Punhani and Mahajan 1989:ii).

There are innumerable volumes of research available on the ICDS; none of them mentions the disabled child and nutrition, or disabled child and morbidity, or the disabled child and immunisation.

It is as if these children did not exist.

7.6 A Concluding Discussion

The outcome of the study at the ground level indicated that the Government's ICDS policy did not include the disabled child into the local anganwadis. The occasional disabled child is admitted, but this is not the norm or the general practice. The disabled child is not entitled to the nutritional supplement either because they do not register for the programme.

The Government does not provide any educational service for disabled pre-school children. The municipal hospitals provided free medical services for immunisation and other diseases. ICDS provided services for identification and referrals. Only the NGOs provided specialist services of special education and treatment. Ignorance about the subject and a lack of awareness was predominant. The disabled child was seen as a medical problem with medicine as a panacea. This situation was perpetuated by excellent services being provided by private voluntary organisations so that there was no need for any other service. The mothers had their own assumptions and beliefs and did not take up the issue with the authorities for the following reasons:

- fear of rejection;
- apprehension about the reaction of anganwadi workers to the disabled child;
- anxieties about management and whether the AW was trained;
- their own lack of education;
- their own protectiveness of their child;
- their hesitancy in approaching authorities and questioning a Government service;

- their own technical perspective of special schools being for special children.

When asked what problems would arise if disabled children were to attend existing anganwadis, the two major problems stated *were* the lack of toileting facility and the lack of knowing how to handle these children. This was a common suggestion from all three groups of ICDS supervisors, anganwadis and parents. This could be due to the sample selected.

Again the mystique behind special education (Tomlinson 1982) that 'professionals' were needed for disabled children, a technical perspective on the problem, came up with all three groups of supervisors, anganwadi workers, and parents. The suggestion from respondents was that the anganwadi workers would need special training to handle these children, special toilet facilities and special furniture to accommodate disabled children. Those in the triangulation sample appeared to be more vulnerable to being exploited by faith healing witchcraft; neither the Government nor NGOs had given any thought to the plight of their disabled child.

The following attitude towards a child with disability were noted:

- stigma
- taboo
- prejudice
- fear
- ignorance

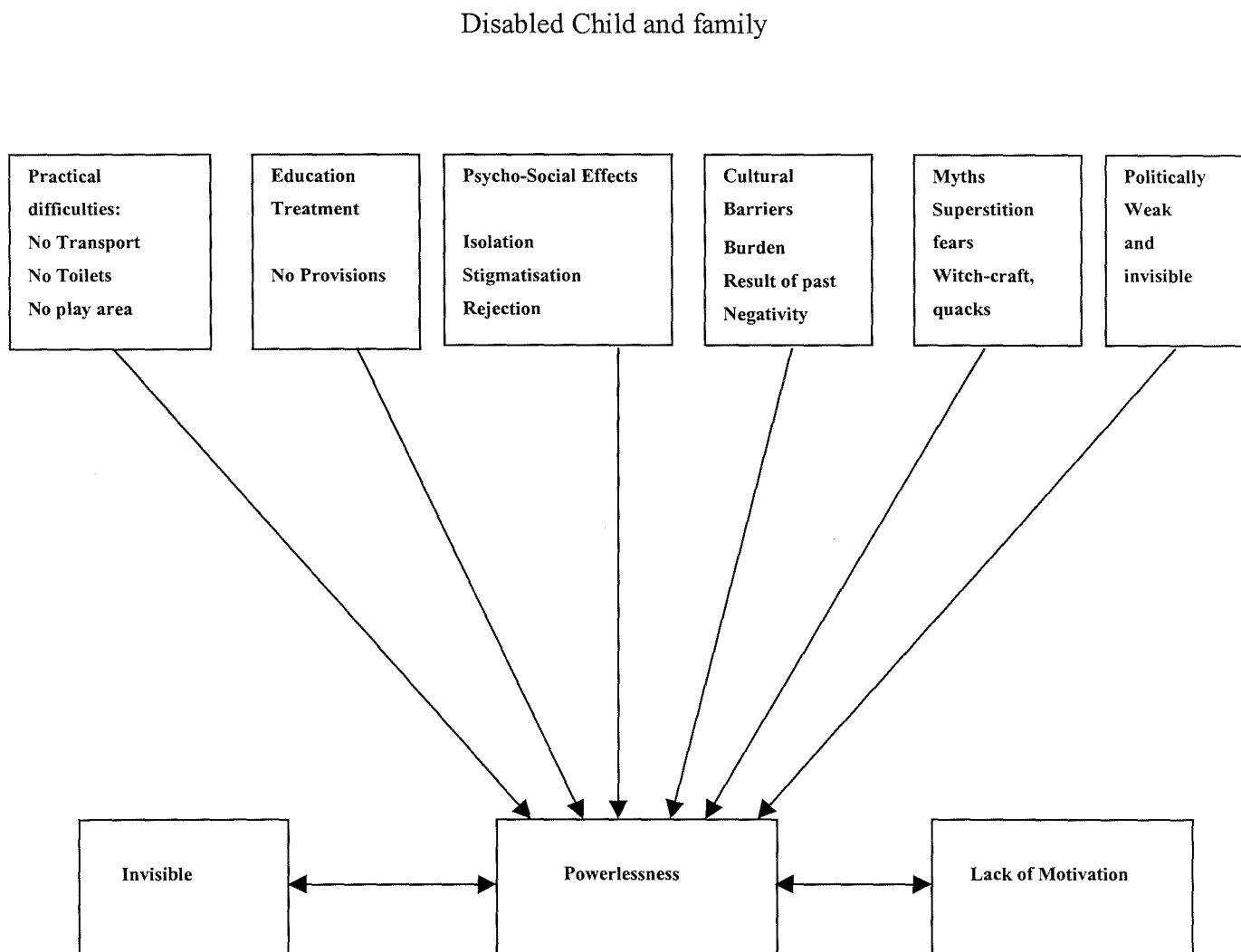
Disability was looked upon as:

- A curse/a result of past deeds
- An embarrassment
- Witchcraft and evil eye
- An individual tragedy
- A 'daughter-in-law' problem

- A personal not a State responsibility
- To be hidden away
- ‘A miracle will happen’
- ‘One day she will be normal again’

Figure 5 illustrates some of the processes and outcomes that emerged from the study.

Figure 5: Powerlessness and Invisibility



Summary

This chapter has recorded the findings from the impoverished community of Dharavi and their beliefs regarding their disabled child. The government did not provide any services for disabled under-fives. The services they did provide through the ICDS did not include disabled children. Some services were available set-up by NGOs. A lack of awareness, ignorance about their disabled child, a lack of any counselling support led the parents to believe that having a disabled child was a retribution for past sins. This had a gender bias where women were made to feel that it was their fault. For mothers, the study indicated a new dimension of the gender bias and the low status of women that exists in India and from all accounts their lives appeared to be a story of harassment and persecution. The disabled child, due to lack of services, suffered from a lack of socialisation leading to isolation for mother and child. The family and the siblings remained stigmatised and confined by this blinkered way of thinking because of cultural ideologies that were ingrained in the community. The children remained in the invisible mould in which they had been cast. People in a survival culture did not seek any change for their child with handicap but were unquestioningly accepting.

In terms of a policy discourse, the ICDS policy was a good example indicating how closely policy formulation and policy implementation processes are linked; and how if the goals and objectives of policy are not clear there will be no policy to implement, how non-decision making and remaining silent on certain issues could suit Government's resource allocation reducing their expenditure in this area; and how those who are powerless and depoliticised are the ones who will suffer most, being kept in their place, invisible and without entitlement.

PART FIVE

THE EMPIRICAL FRAMEWORK

8 POLICY-MAKERS AND THEIR PERSPECTIVE

Introduction

Chapter 8 reports the central issues that emerged from the interviews with the policy-makers, academics and bureaucrats, while discussing the ICDS and the wider issues of the research question. Data were collected through semi-structured interviews that were taped with the permission of the interviewees. The tapes were later transcribed by the researcher and analysed using the Nud.ist software programme to identify recurring themes in the interviews.

The Chapter has been divided into five sections: section one sets out the issues which govern the research question and form the criteria for the selection of the respondents; section two sets out the credentials of the respondents; section three gives a brief description of the Nud.ist methodology used: section four details the main factors that emerged from the interviews and is presented as categories and sub-categories, codified using the Nud.ist software: section four describes the findings: section five is the conclusion. The chapter ends with a summary.

8.1 Issues determining the criterion for selection of respondents

In terms of the broader aspects of the research question, it was important to understand the values and beliefs that the policy-makers held about children with disability. Goetz and Le Compte (1984) suggested that,

Simple criterion based selection requires that the researcher creates a recipe of the attributes essential to the selected unit that

matches the recipe (Goetz and Le Compte 1984:77).

The 'recipe of the attributes' of the interviewee sample (Goetz and Le Compte 1984) had to be carefully planned to generate the body of knowledge, which might lead to answering the research question. The issues around which the questions were planned were based on the conceptual framework of the research question. Therefore, although it was a policy study rooted in educational policy and special educational needs, it overlapped several disciplines such as philosophy, sociology, education, special education, child development, psychology, history, legislation and economics.

Issues covered

Broadly, the issues covered were: the wider historical and political processes, the philosophical and ideological context, the educational and welfare system, the socio-cultural values, the economic constraints, the framework in which policy gets framed and implemented with the central focus on the ICDS policy and practice. Details of the issues are:

1. Areas of policy formulation and implementation; the kind of policy and plan that existed for educating disabled children; the circumstances in which the ICDS policy was formulated and the mechanisms designed for implementation;
2. The ideological and cultural context within which the ICDS practice exists and the factors that could have influenced the policy-makers;
3. The sociological perspective in which policy can become embedded: the underlying value systems of the culture towards disability with linkage if any to deep-rooted values;
4. The historical and philosophical issues: the statement of intent, which appears to have included the disabled child in the main educational framework.

It was crucial that these issues were examined and kept in perspective, in order to come up with a serious finding. Questions were tailored to probe avenues that would

yield information relevant to the research question More details of questions that were used for the policy-makers are in Appendix 5.

8.2 Background information about the respondents

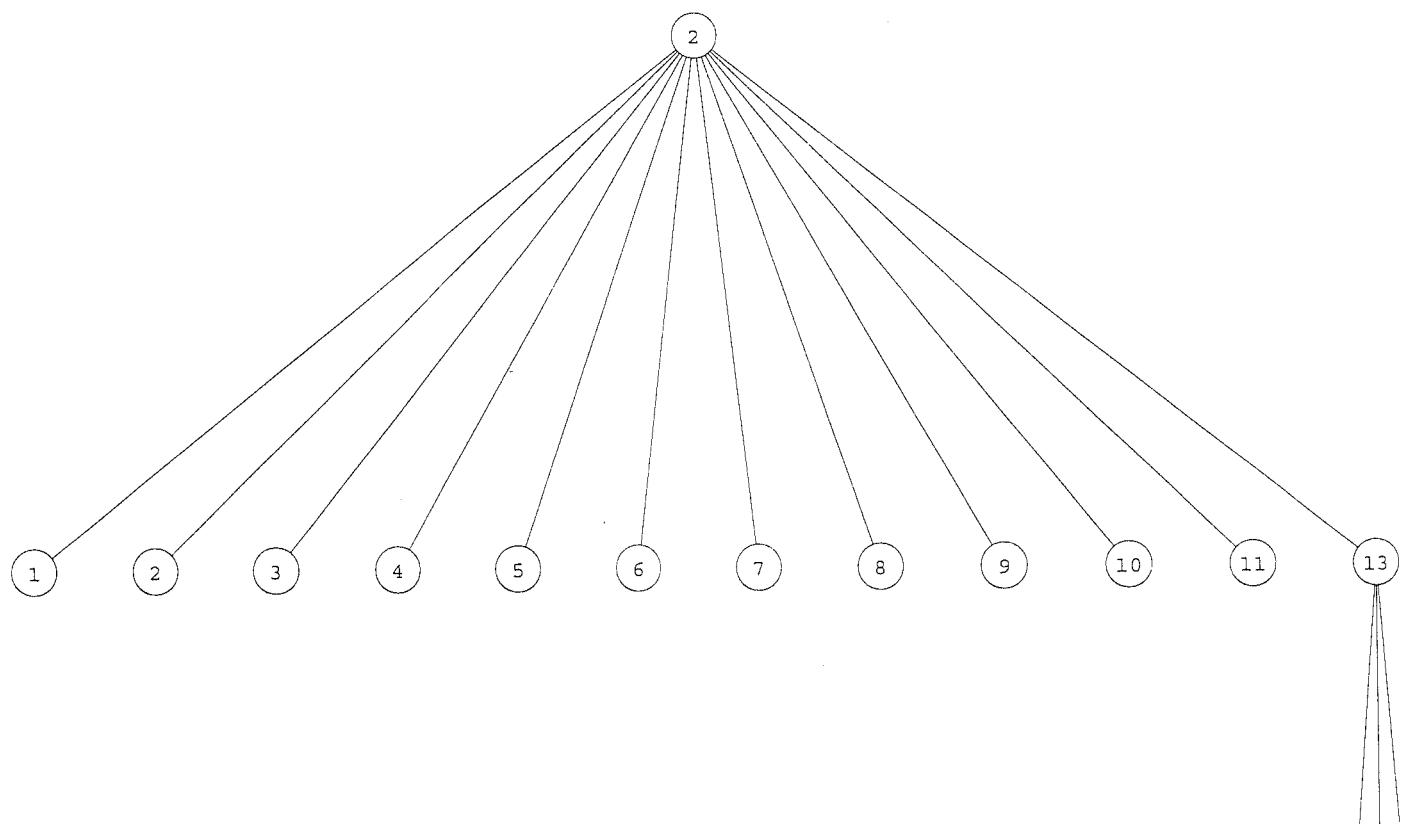
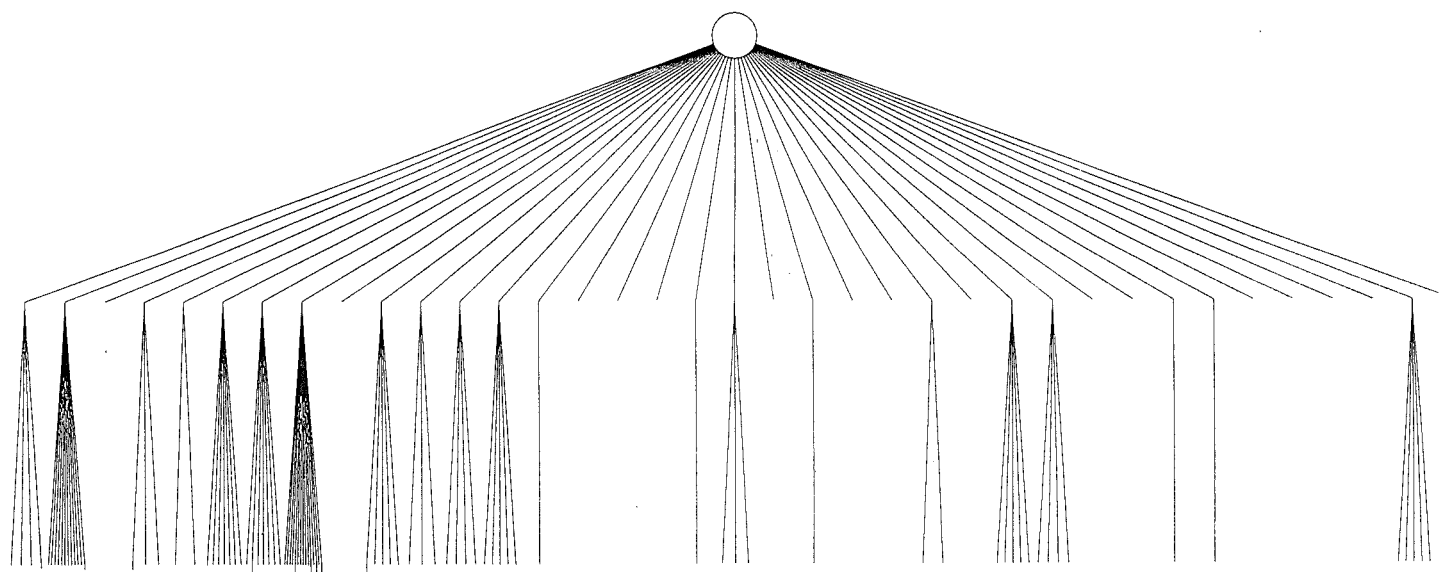
The conceptual framework and the research question formed the foci in the selection of participants. Senior people, opinion-makers, administrators, and those persons involved in policy formulation and policy implementation holding positions of influence in public life were criteria used for selection. Therefore, the kind of 'attributes' that they possessed, which agencies or organisations they represented, *the kind of thinking* they represented, the positions they held, were the 'criterion based selection' (Goetz and Le Compte 1984) used in determining the selection.

Twenty-five people, principally located in New Delhi, the seat of the Government in India were selected for the sample. They were involved in policy formulation and policy implementation, civil servants in the Ministries of Education, (HRD) Welfare, and the Planning Commission as well as involved with the ICDS; academics in the disciplines covering education, early child care, pre-school, special education, teacher education; researchers, parliamentarians, economists, social and political activists on gender and disability issues. They were individuals who had an informed perspective and whose position rendered their perspective noteworthy (Glaser and Strauss 1967). Known for their contributions in different fields, they were key people involved in policy-making and had a knowledge base about policies and policy-making. The study being exploratory and open-ended, it was important to select the sample carefully so that it was relevant to the research question and the wider conceptual issues that was being investigated.

The twenty-five respondents selected, fulfilled the following criteria:

- a) Those involved in the ICDS policy directly or indirectly; (Anil Bordia, Pradip Roy, Binu Sen, Professor B.N. Tandon, Adarsh Sharma).
- b) Those working for the Government in the Ministries of Education and Welfare, the Planning Commission: in organisations dealing with the ICDS policy as well as the

Figure 6: THE NUD.IST TREE



general policy for disabled person (Professor Sharma, Chitra Naik, N.K Jangira, Gowri Chatterjee, Vineeta Kaul, Anupam Ahuja, Neerja Shukla, Prof. Arora).

c) Those eminent in their own field as authors, researchers, academics, civil servants, having written books on economics, law, education, disability (Nani Palkhivala, Bimal Jalan, Rajmohan Gandhi, Armaity Desai).

d) Those who have contributed to the evolution and development of the Indian situation within their own fields (Chitra Naik, Anil Bordia, Nani Palkhivala, Rajmohan Gandhi, Bimal Jalan, Brinda Karat, Bika Karlekar).

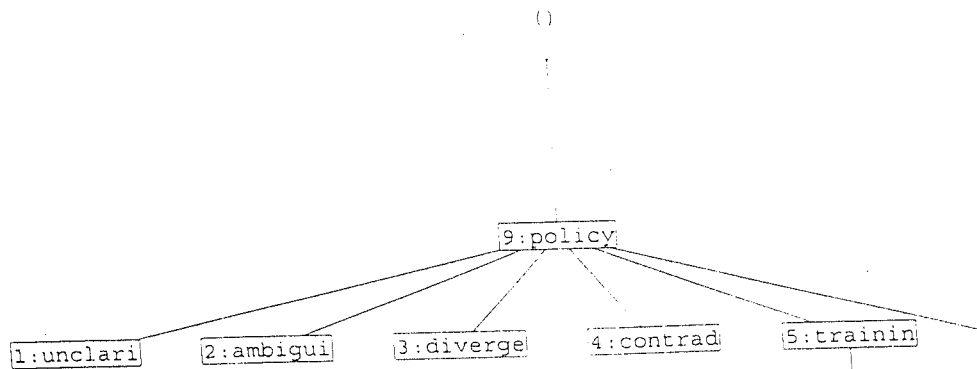
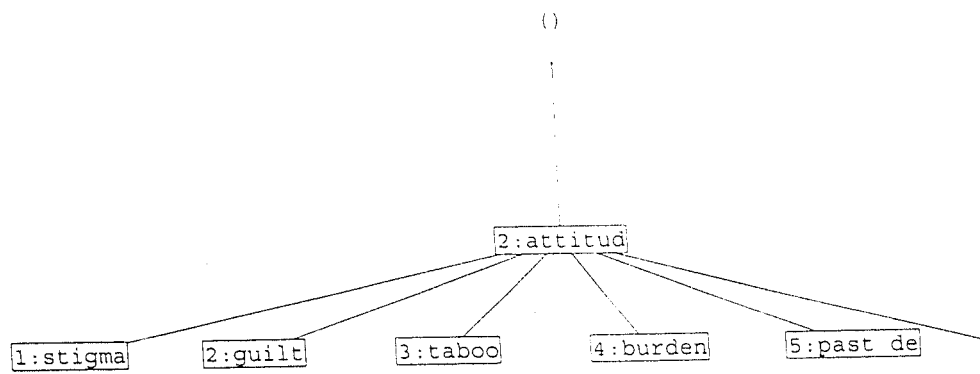
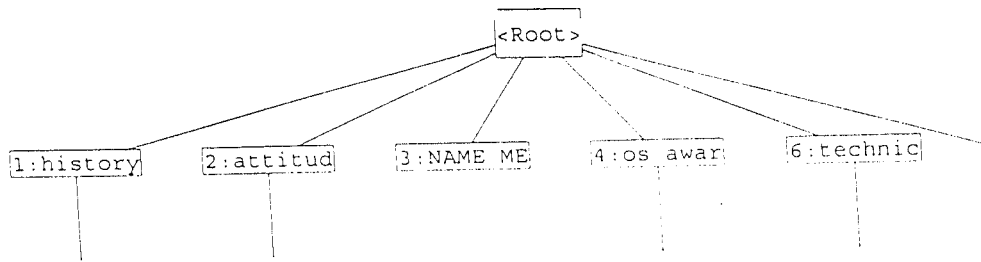
The respondents profile and the positions they held when the investigation took place are detailed in Appendix 9.

8.3 The Nud.ist software

The interviews tended to be long, as the respondents were articulate with a great deal to say. As mentioned earlier in the Chapter on Methodology the amount of unstructured data that the study had generated was voluminous, 75,000 words, that needed to be structured and put into order. Again as mentioned in the Chapter on Methodology, Nud.ist, a software programme generally used to structure large quantities of qualitative data was used. In the Nud.ist the categories are displayed in a graphic form of a Tree. An example of this Tree Form with its branches is displayed in Figure 6 overleaf. The branches are called nodes and from the nodes, subcategories called children and siblings can be created; Figure 7 overleaf displays the nodes and sub-node; in the third example the parent node is policy which has sub-nodes or children: they are unclarity, ambiguity diversity, contradiction, training: training has siblings (not shown) but which included anganwadis, teachers, bureaucrats.

Because of the speed with which it can retrieve information, the consistency which it maintained, the flexibility with which one can create nodes and sub-nodes, the linkages and relationship which one can establish one can say that the Nud.ist software is an extremely useful tool for analysing the large volume of qualitative data gathered although its time consuming.

Figure 7: NODES and SUB-NODES in the NUD.IST



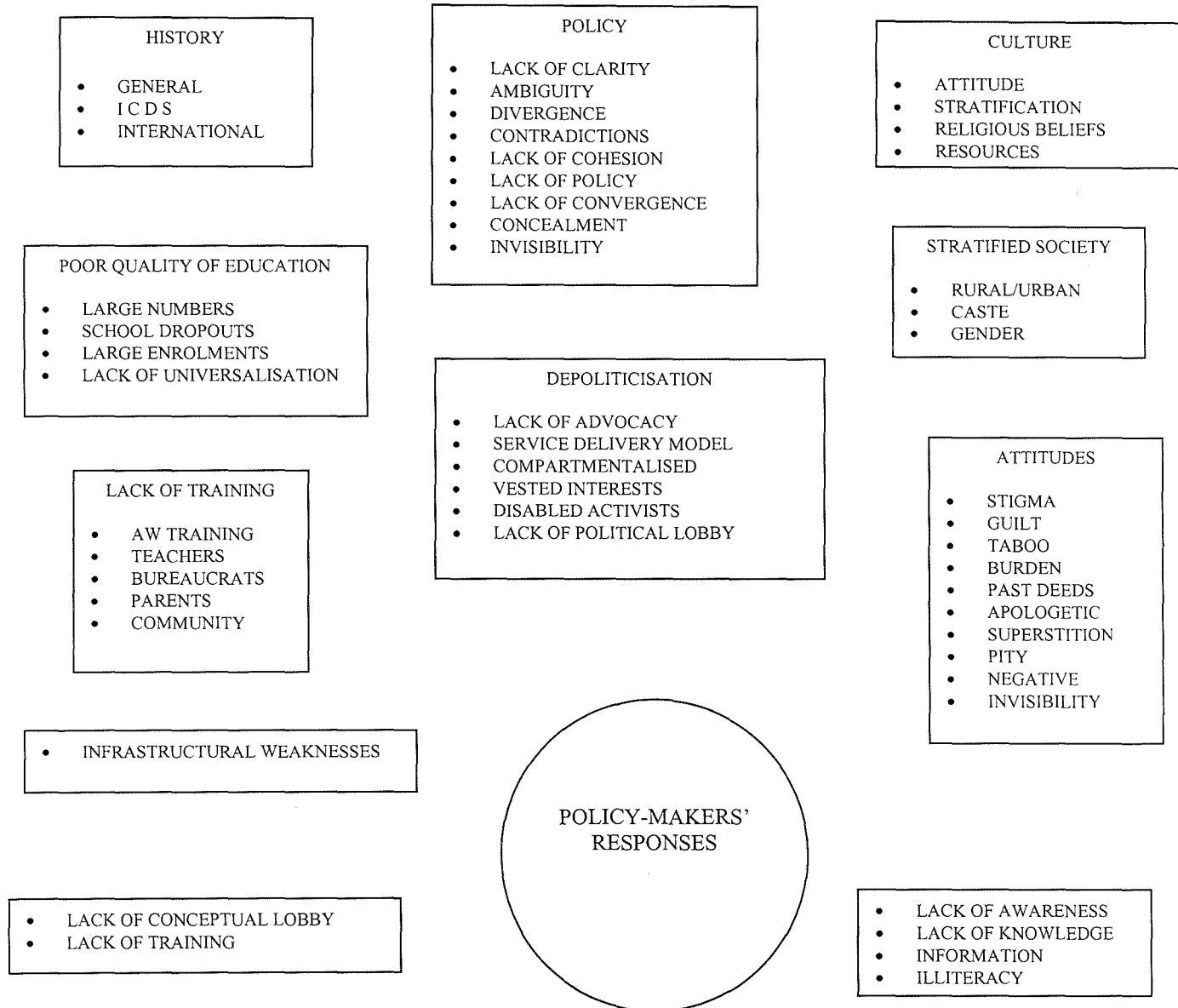
8.4 Key themes that emerged from the respondents

This section presents the principal outcome and the factors that emerged, from the respondents. The historical factor will not be dealt with separately as it runs through all the issues. The categories and sub-categories that emerged from the responses are shown overleaf in Figure 8 entitled: An Illustration of responses of the Policy-makers

The main factors that emerged are:

- policy issues
- policy and the educational structure
- the social-cultural and ideological value system
- the social framework
- The politics of policy making
- depoliticisation
- the difficulties of the policy-maker
- size of the problem
- the conflict of resources

FIGURE 8: An illustration of responses of the Policy-makers



8.5 Report on the findings from the policy-makers

The report begins with the findings as far as the ICDS policy and practice is concerned and moves on to the wider issues in which framework the ICDS is embedded. Many of the issues raised by the informants overlapped; extracts are given to illustrate the points.

8.5.1 Policy issues

(i) Policy Formulation Stage

Policy Issues took up a major portion of the text units in the Nud.ist analysis. Discussing the policy formulation stages, Ex-Secretary of Education, Anil Bordia said about the ICDS project,

It was launched in 1974 ... it took a long time ... the design of the pilot ... money to be provided, money from overseas ... it all took time ... the project started in a pilot phase in 1974 ... I was in the Education Ministry at that time.

Regarding the issue of children with disability,

I don't remember any debate or discussions having taken place on disabled children...and it is the children with disability who could have benefited so much. If we had brought them into the programme back in 1974/75, by now they would have had at least 20 years of rich experience.²¹

He went on to say,

A very large number of colleges of Home science, Child Development Centres,

²¹ After retirement in the early '90s, Anil Bordia set up a community-based service called Lok Jumbish dealing with primary education in the context of universal education in Rajasthan which includes disabled children and which was earlier reported in the literature review.

Baroda etc., all came together. They were commandeered to develop this three months' training programmes ... but as far as I remember this group was never mentioned. In recent years what I notice is that government is not unwilling to recognise the special needs of children with disability.

Anil Bordia discussing the issue definition describes,

In our Committee of 72 members, while planning for the ICDS, there was a person called P.N.Ghai Medical and Health Advisor to the ICDS and then subsequently B.N. Tandon became the Adviser. Ghai as far as I know, never really reminded us that there was another category of children to be considered.

He mentioned that 'there are *volumes of evaluative research*'²² over the years done by several organisations, but the disabled child does not figure in any volume'.

Dr. Anita Verma, child development authority, from M.S. Baroda University discussing the formulation of priorities for the programme said,

You know, what I think is that this has not been thought of at all. When people say they don't come to the anganwadis, its because nobody has ever thought that there is this group of people who should be included. Therefore, something needs to be said about it in the policy.

Anil Bordia described,

To come back to ICDS, I once looked at several evaluations, which were done by Pradip Roy, who was responsible for evaluations of ICDS, for many years at the Council of Social Development. In fact you will find that in the Library there are

²² Whenever italics have been used in the text of the answers, it indicates the respondent speaking with a degree of passion.

volumes of evaluations, but children with disability just do not figure.

Dr. Pradip Roy, of the Indian Council of Social Development in New Delhi, who had led the team for the first pilot study done of the ICDS programme in his interview said that ‘children with disability had not been a part of the policy agenda.’

‘It was an issue that never came up for discussion’ he said. The ICDS, he explained, had begun as a nutrition-monitoring, rural-based programme, with a Health thrust to decrease child mortality and improve the health of the mother. It was supposed to be a continuation of the Applied Nutrition Programme, which had gone on from the mid ‘60s supported by Government of India and UNICEF. The main philosophy was to supply diet and supplementary vitamins that would hopefully increase the health of the mother and child. The whole scheme was child-centred, to be used by the grassroots anganwadi worker. It was to be an innovative community approach to be run at the village level and tied up with the Panchayat Scheme (The Village Network Scheme).

Dr. Pradip Roy explained,

The ICDS was an extension of the Basic Needs Programme which ILO and UNICEF had devised. The main philosophy behind the ICDS Programme was nutrition and health.

An ex-official of UNICEF explained,

The point was that UNICEF felt that if we looked after any of the specialised groups that needed attention we would divert attention from the main aim which was universalisation of education, so as a matter of conscious policy, I remember although this may not be written up anywhere, certainly in our internal discussions we felt that we would not, initially admit into ICDS, or divert the issue by taking in side issues like disability.

Looking at the historical evolution of UNICEF by the mid '70s the primacy of education had not been there. UNICEF concentrated on Health issues. With limited resources and faced with gargantuan problems, UNICEF tended not to address smaller marginal groups.

People who framed the ICDS Scheme, who planned the preliminary work, started the pilot and did the evaluation. I think that these people just didn't know all these things (Anil Bordia).

Anil Bordia explained,

I think the reason for the exclusion of disabled children is just a lack of awareness, lack of training, lack of education.

(ii) Policy Implementation Stage

When the respondents were asked, whether the policy and the practice, as it was functioning now, had actually left out disabled children from their planning or not, they confirmed that it had. Dr Adarsh Sharma, Deputy Head, NIPCED, in charge of the curriculum and training of ICDS personnel said,

I mean this component is virtually defunct.

It is not written anywhere in the ICDS scheme that *don't include disabled children*; we have put in early detection of disability into our curriculum since referral services are an integral part of the ICDS programme, but the anganwadi worker is only expected *to identify those children who are not normal through home visits and refer them elsewhere*.

Professor Sharma said that the ICDS policy was ambiguous about disability.

It does not mention anywhere that they should be excluded but nor does it specify anywhere they should be included.

Professor Jangira (special educationist, in the World Bank) when asked was it a fact that disabled children were not included in the ICDS programme said:

Yes, it is 100 per cent correct! The Ministry of Education's main goal, during post-Independence, has been universal education *without including these children*; so is the case with ICDS ... nobody bothered; except for some special schools the Ministries of Welfare ... Education never bothered. It is the same position for the ICDS.

Confusion about policy objectives came up when the senior bureaucrat in charge of the ICDS said 'she did not know that disabled children were not a part of the agenda of the ICDS practice' and in fact said she had seen a few in a nursery:

Yes, I have myself seen some children who were not physically handicapped but may be mentally disturbed, in Tamil Nadu (a state in the southern part of India). I have seen them.

Again she mentioned the weakness in the scheme.

I think the anganwadi worker may be able to identify but they will not be able to handle the child. The anganwadi worker can identify and refer the child.

Lack of clarity in policy regarding training and the role of the worker was mentioned. Professor Kaul, Head of Pre-school and Primary Section of NCERT handling the training of pre-school teachers felt:

I think to some *extent there is not adequate clarity regarding what the anganwadi worker is expected to do*. The orientation programme is inadequate ... we work a lot with the anganwadis and we do demonstrations with children. Invariably there are some children who are very

quiet, not participating and you ask the anganwadi worker ... and they make blanket statements that this child is 'mand buddhi' you know mentally retarded and the child looks absolutely all right - so if any child is not participating – he or she is mentally retarded.

This happens very often, and wherever, there is a more visible and serious sensory disability, which prevents the child from fully participating in the programme he is referred else where, as the anganwadi worker does not have the necessary skills or the necessary abilities and training how to tackle them. *I think the training component is not strong enough.*

Regarding the question of whether the disabled child received nutrition or not, the respondents directly dealing with ICDS, Professor Kaul (NCERT), Dr Adarsh Sharma (NIPCED), Senior Joint Secretary, Binu Sen, (WCD) confirmed that they did not.

Binu Sen stated that:

No, they do not get it, only those who are registered get it.

Anil Bordia repeated several times 'I don't think the disabled child figures anywhere'.

I think that there is overwhelming evidence to show that this particular subject has been out of consideration at any prominence, at any level of commitment in ICDS. I think there is enough evidence to show that (Anil Bordia).

8.5.2 Social system: environmental barriers

Dr. B.N.Tandon, Chairman of the Central Technical Cell (or CTC) the research monitoring and evaluations arm of the ICDS, as well as one of the architects of the

ICDS, was irritated with the research question and felt that the question of non-inclusion had happened because of a lack of mention in the policy documents.

The answer is very simple. We do not want to exclude. *We have not excluded...* its just the situation in the village itself... because ... the mother doesn't bring the child. She doesn't ...leave her there for 2 hours...then how can the AW look after this child... so there is no planned exclusion.

He went on to say about the parent,

'I will not put this child along with that child', this is her thinking.

It is not that *we have excluded* ... awareness generation has to be done by somebody else and unfortunately the anganwadi workers cannot do it as they have their limitations.

According to Dr. Tandon if one examines any programme,

The whole question of *the barrier, which exists within the family*, the parents in the social structure must be taken into account. *That barrier is the main issue.* Rather than policy decision by anyone, neither by the zilla parishad, nor by the gram panchayat (Indian village government institutions) nor by the State Government, nor by the Central Government: *nobody is putting up the barriers except the families themselves.*

He was emphatic about the fact that the research question was very easy

... for me to answer and the very clear-cut answer is that there's no policy decision to exclude these children. These children are not coming, *not because they are excluded but because of the family, there is a social exclusion within the existing civilisation* ... the village.

Dr. Tandon pointed out that these barriers were solely social, due to the parents. He also mentioned that it could be a lack of 'networking' between agencies as he went on to say,

Existing services ... the infrastructure ...
social workers the departments of Rural
Development, and Women and Child have
not done much networking.

According to the senior bureaucrats the ICDS was supposed to cover 'all children' including children with disability. Anil Bordia explained,

I think the reason for the exclusion of
disabled children is just a lack of
awareness, lack of training, lack of
education.

The lack of clarity about whose role it was to suggest ways and means to include disabled children in the programme came up. The Ministry of Welfare, according to some of the respondents, was the nodal agency and was supposed to suggest ways of including children with disability but had not. However, an important person, senior Joint Secretary in charge of disability (Gowri Chatterjee) did not think it was feasible to include disabled children into the ICDS programmes and said,

We have to think in terms of reality ...
practical situation on the field. If you take
the position of the anganwadis and the
helpers, are they really equipped to deal
with a disabled child?

There are certain drawbacks that is the
problem ... the training input needs to be
strengthened ... to reach the child to the
centre is a problem.

It would be difficult to reach the disabled
child to the ICDS Centre.

About the training and about bringing the child to the Centre, Gowri Chatterjee added,

... so it is not as if the ICDS is not
including disabled children, they are

included, but in practice it's a difficult thing to do.

What comes up is that the key person dealing with disabled children, from the Ministry of Welfare whose role is to educate other ministries about the needs of the disabled child, is not clear about how to integrate the child into the ICDS nor does she ideologically believe that it should be done.

8.5.3 The Wider Issues in Terms of Policy: Conceptual Issues

Dr. Armaity Desai, Chairperson, University Grants Commission, felt that 'the reason for a lack of cohesion in Government policy was the lack of proper definition and conceptualisation of the normal child'. Instead of keeping the child's needs within one Ministry, she said, that the Government had put 'the child in different ministries'.

Disabled children have been allotted to the Ministry of Welfare, children used for work have been placed in the Ministry of Labour, street children have been put with Welfare, the socially disadvantaged child is the responsibility of the Ministry of HRD, Department of Women and Child (being the target group for the ICDS); the education of the normal child is with Ministry of HRD; adoption is looked upon as a disability and therefore comes under the Ministry of Welfare.

The administrators and bureaucrats had complained about this 'compartmentalisation' as they called it.

These are very artificial divisions for all of us and not a very fruitful one, we have complained several times but nothing has happened (Dr. Desai UGC).

According to the respondents who were involved closely with the Government machinery, a lack of conceptualisation about the differing needs of the normal child as well as the disabled child, combined with the interdepartmental confusion over each one's roles, were a few of the factors that had contributed to an uncoordinated delivery of service.

8.5.4 Structural Issues

Referring to the division of the Ministry of Education into HRD and Welfare, Dr Armaity Desai, Chairperson of UGC said,

Having created such an omnibus Ministry with two ministries, two secretaries nobody is going to want to club it together because there are many other benefits: political and bureaucratic (Dr. Desai UGC).

The Departments of Education, IEDC, DPEP, WCD, within the Ministry HRD had not come together to work out how to include disabled children into their programmes.

When you want to integrate a child, unless both the Ministries work together on an overall plan for children, there will be various gaps in which the child will fall, and this is happening (Dr.Desai UGC).

The lack of co-ordination as a factor contributing to uncoordinated services was mentioned. Vineeta Kaul, dealing closely with the ICDS programme said:

There are so many Ministries in the GOI ... the child is divided into so many compartments that you really can't help them in a co-ordinated manner ... generally the Government contradicts itself.

The respondents who were working within the Government system said that the 'fragmentation, the ambiguities and contradiction of Government policy strongly came through as a cause for the divergence in activities' (Desai, Kaul, Sharma, Jangira).

There are so many ambiguities and contradictions ... and then we hope for convergence, which doesn't exist or rather we plan for convergence, which doesn't exist (Vineeta Kaul).

Professor Sharma, Director of NCERT, summed it up and said:

Really nothing can happen unless there's better co-ordinated effort amongst the two ministries of Welfare and Education to look at the child with a co-ordinated focus and that will give us the results we are looking for.

This lack of interdepartmental co-operation which could have contributed to fragmentation in terms of policy came up.

I was expecting something would happen when the Ministry of Human Resource was created and these departments were brought under the same Ministry ... but these departments remained fragmented in terms of policy ... in terms of programme ... in terms of activity (Jangira, special educator World Bank).

About the ICDS, which was dealing with the critical 0-5 pre-school years, the question that was raised several times was, how was it continuing in the Department of Women and Child which had a health thrust and not with the Department Early Childhood Care which had an educational thrust. This I soon realised was a very politically sensitive question. To understand this one had to go back into the historical background when ICDS was initially started. At that time the ICDS had only the health and nutrition component and was being administered by the Ministry of Welfare as well as the Food Ministry which was supplying the nutrition component through FAO. Around the '80s, there was another scheme called the Early Childhood Education Scheme, functioning within the Education Ministry. When the Department of Women and Child was transferred to the HRD Ministry from the Welfare Ministry, the secretaries took a decision that the 'early childhood component' of the ICDS should also be the responsibility with the Department of Women and Child (WCD). With this move, the project's social component of the ICDS programme did not get the focus it needed.

According to child development researcher, Professor Vineeta Kaul of the NCERT, 'this was a very wrong move' which resulted in 'a chaotic divergence in the delivery of service'.

The Department of Women and Child have a larger budget, and the component of early childhood care does not get the importance it deserves.

The following difficulties of ICDS being administered by WCD were put forth by a number of respondents:

- Early childhood is not being given the kind of stress it should be given.
- The major vehicle of early childhood education is ICDS but it essentially had a health thrust.

About the larger issue of the lack of pressure in including disabled children, Senior bureaucrat, Gowri Chatterjee from the Ministry of Welfare confirmed that:

We naturally do not have a separate policy for education but we do have a policy for rehabilitation. The Welfare Ministry cannot cater to the educational needs, the employment needs the other training needs, the medical needs.

We are only the nodal Ministry and we have to pursue other concerned Ministries to persuade them to take action so that they include disabled children in their programmes, and make adequate budget provisions so that they implement the actual services.

A clear role of the Ministry did not come through. Although policy existed, the question of whether disabled children should go to a special school or an ordinary school still seemed to be a confusion in the minds of senior bureaucrats. The Joint Secretary in charge of promoting integration himself seemed confused about this. When asked among other questions why disabled children were in the Ministry of Welfare and not Education, he answered:

Do you really think special education should be with us?'... quantity is favoured to quality. I think at this stage integrated education will be our speciality only for people who have very limited handicaps; whereas special education has to be there for the child with severe special needs.

A strong enough commitment to integration does not come through; a lack of conviction comes through and the desire of most bureaucrats to reach a larger number, 'quantity is favoured to quality' seems an unconcealed message as stated here.

Another difficulty that was mentioned was the dichotomy of roles between the Ministry of Social Welfare and the Ministry HRD. The respondents felt that this was 'a very serious problem coming in the way of delivery of services' and was due to the fact that HRD was promoting integration while the MOW promoted segregation.

Time has come if 'Education For All' is to be achieved, that good heart searching in this area takes place, and, either jointly between the HRD and the Social Welfare, or singly by the Ministry of HRD, this problem of disabled children is sorted out (Respondent).

Mrs. Chitra Naik, Adviser to the Planning Commission on Education and Welfare had accepted that 'this was a serious problem', and had suggested that action should be initiated.

Getting together people from both of these two Ministries to agree upon a common strategy of action and later on, one can decide which place the disabled child should really fit best.

Apparently there was some discussion to this effect going on in the 9th Plan.

But once an area has been given to a particular Ministry, to take it away or to wean it away from them requires a lot of discussion and time (Jangira, World Bank).

But my hunch is that the Ministry of Welfare would fight its battles to keep the services. However, we should be interested in getting things done. (Respondent).

What came through, was that inter-ministerial convergence was not happening. The Ministry of Welfare, as a nodal agency was not being able to provide the leadership required for this.

Every Ministry has a tendency to cling on to what they do; if the subject gets out of the Ministry of Welfare the Joint Secretary Welfare would have to leave her department and go to the other ministry ... I mean HRD Ministry ... there again would be at least 2 departments which they would be dealing with - Department of Women and Child Development and Department of Education. ICDS is with Women and Child Department; disabled children are with Welfare. I think a very important point that is coming in the way of a co-ordinated approach is inter-departmental problems (Ex-Secretary Education).

The most important problem of lack of quality in present day education came up. Speaking about the major problem of dropping out of school before finishing, a host of factors emerged. Professor Sharma said that,

... most of the problems are that basic education that is being imparted even in a formal setting, is not of an appropriate standard or quality ... it doesn't take into account the basic concerns of the child, every child has some limitations. Rigidity of curriculum ... one curriculum for all ... in a uniform manner with no modifications available and too much emphasis on examination on the entire educational processes are not the answers. These have become some of the deterrents in the lack of quality within our educational framework ...

The schools were reeling under the pressure of showing good results. Results would be affected and questions would be asked, and this was one of the reasons why they were not willing to admit disabled children. The examination-gearred school system, which currently existed, was not the best approach in a country like India where vast numbers of children were used for labour in the fields and in the households. It was mentioned that the entire general educational framework that included curriculum, school timings, teacher training, quality of instruction in the class, pedagogic methodologies all needed to improve.

Dr. Tandon felt that 'convergence' was the answer. 'Convergence' was a term that was used frequently by the respondents. It meant that the various departments of the Ministries were not coming together in dealing with the issue. It was not being addressed with a consensual approach.

Whatever has been tried in the periphery works, we need to expand the convergence to the Ministries, to the officials (Dr. B.N. Tandon).

According to him, on the top level, although ideological changes were being reported social percolation had not taken place, 'activities of sensitisation, raising of awareness had not been begun on this issue, by either of the two Ministries.' Dr Tandon insisted that 'the confusion was at the top' and called the functioning of the ministries 'a top-down approach'.

A lack of convergence at the top level is the problem. There are contradictions between top and bottom level. It's not the lower level it is the situation at the top (Dr. Tandon).

He continued to say that in the field level

A bottom-up approach is needed, and this is what we are trying to do. Bringing disabled children into the mainstream is absolutely essential and must be done.

8.5.5 A conflict of resources

Another reason given by the respondents was the lack of priority given to the issue of disability. The main goal for so many years dominating the administration and bureaucrats in India had been to provide universal education, 'the battle for literacy has not been won yet' said Champak Chatterjee, Joint Secretary, in charge of Integrated Education for Disabled Children (IEDC). Again, a key person responsible for integrating disabled children was not committed to the issue. He went on to say that the policy-makers were

... engrossed with larger more pressing segments of the population; reaching the larger sections of the public ... and the disability segment only constitutes a minority.

To the question whether education should be prioritised only for the able-bodied first, most of the text units on the Nud.ist analysis showed that the respondents believed that it should be very much on a parallel level but remained confused and concerned about the huge problem of Education For All not happening and all normal children still not being able to access education.

Universal education for all normal children had not happened; therefore, it was difficult to think of disabled children who were only a small segment in this vast sea of problems.

Professor Sharma summed it up in that the lack of resources may have led to 'a screening away of the problem'. R.S. Pandey (Joint Secretary DPEP) who was previously in the Ministry Welfare and now in the Ministry of HRD in charge of the DPEP programme said.

There is a resistance also amongst the bureaucrats to allocate funds for the disabled group. The policy-makers in the Planning Commission have been reputed, not to take disability issues seriously. There is a struggle to get anything done with the Planning Commission (Pandey, HRD).

With reference to meetings with the Planning Commission, he said, whenever the disability issue came up ...

There would be lectures about 'there could be many cheaper ways of doing all this ... why don't you talk to some NGOs' (Pandey, talking about the time when he was Joint Secretary, Welfare).

An academic who was a child development authority felt that,

They are not looked upon as human resources, they are looked upon as a burden on our *meagre* resources ... they cannot do anything with their lives, so why spend a lot of money (Anita Verma)

8.5.6 Social Issues: a lack of awareness about the disability issue amongst the policy-makers

What also came up as explained by Dr Bimal Jalan (Secretary Planning Commission) is the lack of knowledge amongst the policy-makers themselves.

It's still an area of darkness ...when you first started thirty years ago the lack of knowledge was there even now, people are not aware of what needs to be done, the lack of knowledge ... however it's changing; people understand blindness, people understand deafness, but in the old cultural position it is supposed to be the individual's fault that handicap happens. I don't know ... its a lack of education in our culture ... Its a question of information, knowledge ... our teachers are not trained to handle disability however small.

According to some experts in the field, this lack of knowledge amongst the policy-makers themselves led to a lack of understanding about the disabled child.

... there is the feeling amongst the administrators and the senior policy makers about what could they (disabled children) really do? Was it worth the effort taken in the way of manpower and

financial resources? (Respondent from NCERT).

Again the question of 'let's show results where they'll easily come' was perhaps also somewhere at the back of the mind of the policy makers. Anupam Ahuja (Special educationist and researcher at NCERT) said that,

Maybe without even realising, the policy makers have also bungled it, and that is how precisely now we have woken up with a sort of vengeance to undo what we have not been able to do for this group (Ahuja NCERT).

Sociologist and researcher in the Women's Study Group Bika Karlekar, explained:

I think it's a lack of clarity, prejudice and probably not knowing how to deal with that kid ... unawareness ... lack of awareness ... how will I as an AWW with very limited awareness, how am I going to deal with this kid? I have 100 hollering kids. I don't want another one who is disabled. Keep the disabled child at home ... these are the explanations ... So all I am saying, it's not just a question of important commissions and committees it's what have you got on the ground? It is NGOs and activists on the ground level who can make a difference.

Largely what emerged was that a lack of knowledge on the subject of disability was all pervasive, involving all strata of society in the country.

Training needed

Chitra Naik (Adviser to the Planning Commission for Education and Welfare) felt that in the area of training the National Council for Teacher Education (NCTE) which was a semi-autonomous organisation involved with training of teachers in the country, could take up training as a special activity,

With education becoming a fundamental right for all children something had to be very seriously done to bring these children

into the ambit of education. This required a new kind of a teacher, and perhaps the NCTE can take this up and the teachers themselves motivated to convince the parent (Chitra Naik).

If there was some policy which could augment the strength of the schools by having a special teacher, the schools would then probably shed their reluctance to get on to this kind of a social responsibility (Professor Sharma NCERT).

Professor Sharma, Director of NCERT added that schools were not willing to take the responsibilities in admitting a disabled children into the classroom, as teachers felt it was an additional responsibility and something they did not know how to cope with.

Many of the respondents suggested that this is because of a total lack of training for teachers.

NCTE and DPEP both dealing with teacher education, were still to dovetail into each other. The existing Institutions for Teacher Education such as NCTE, NCERT, NIPCED, all national level Institutions churning out a huge population of teachers, and par-professionals do not have disability as a component in their curriculum (Respondent).

The reasons given for the lack of coherence in the area of training were:

- A lack of co-ordinated training for the pre- and in-service areas.
- Dysynchronisation and mismatch: sometimes training given but the school system not geared to absorb the teachers or the children.
- No financial allocation to resource support teachers or assistants to teachers for proper integration to take place.

Professor Sharma, Director of NCERT (equivalent to NFER in the UK) said,

It cannot be denied that a very large section of people even in the field of education has not come to grips with this kind of a child.

Several civil servants mentioned that sensitising the anganwadi workers in the ICDS programme was not enough. Training and sensitisation of bureaucrats, politicians and members of Parliament were equally important to remove faulty misconceptions. Some of them mentioned that some senior bureaucrats today are very supportive of disabled children and interested in integration of these children into existing mainstream services, but they did '*not know how to put policy into operation*' and that 'this is the main gap'.

8.5.7 The Cultural Factor

Bimal Jalan (Secretary Planning Commission) went on to say that:

It must be a cultural problem in which a society divides people into different categories, and are reluctant to accept handicaps which are not of their own making.

Nani Palkhivala (Supreme Court Advocate) argued that strong religious biases came in the way of progress in India.

I think it is the limitation of our culture. An Indian is taught that, what you are in this life is the reward or the punishment for what you have done before, so if a man is blind, or deaf or handicapped in any way, it is assumed that he or she is paying for his past Karma ²³, and this is deeply ingrained.'

Nani Palkhivala went on to say,

I am afraid that it is a mind-set of centuries.

²³ Any kind of disability is seen as some kind of punishment for past deeds. This rose out of the basic traditional Hindu belief in reincarnation and that lives were a cycle of births and deaths, and that one is born and reborn until one attains nirvana or moksha (freedom).

Although there is a Constitutional directive and statement of intent to include all children he felt that this ‘meant nothing’ as it is attitudes to disability that needed changing.

Even if the Constitution gives a directive
nothing will happen.

It will take a few hundred years. Karma is the real philosophy of Hinduism, that if I do some good I will get the good, if I do some evil it will come back to me, that is the doctrine of Karma. Karma does not mean that if a man is unfortunate you don’t come to his rescue.

Some respondents felt that policy-makers would certainly not be affected by this stereotypical mind set. Again, some believed that policy-makers, being a reflection of society, may not talk about it bluntly or take it seriously enough to affect their work in depriving the disabled of their rights, but they would be affected.

Moving the discourse further to whether the Karma Theory (past Life) is more prevalent amongst the illiterate, some felt that this was not necessarily so. The Karmic Theory was very strong in India. One of the respondents strongly felt that ‘there was also another culture where people feel that if you help a disabled person, you are going to make your next life better so they consider their service towards them to be sacred’. However, most of the informants agreed that there was a stigma which was connected to the ideology of past deeds and that this kind of belief would only affect action in the semi-literate parts of Indian society.²⁴

Discussing the semi-literate population, the wider social fabric of Indian society, the kind of message that came through was disability was ‘not seen as something normal or natural,’ disability was seen as an ‘evil eye’.

Guilt, stigma and fear dominate families.
All kinds of non-scientific explanations
for disability exist.

²⁴ About 52% percent of India is illiterate

It is a very complex issue; from not only cultural point of view and parents, but also the totality of the social structure which neglects it.

Several respondents felt that the marginalisation that had taken place was due to families and parents themselves believing strongly, that disability was a result of past deeds and that there is a

... feeling of guilt and a calamity being entrenched into their psyches. Parents, by and large, even today, are very apologetic about having such children and they prefer to keep them at home (Respondent).

Dr Desai (Chairperson UGC) went on to explain the cultural mind-set:

Something wrong with me ... evil designs you know, something occurred way in the past which has attributed to these problems ... these things very much exist even today in our society.

Bika Karlekar (Sociologist and researcher from Oxford University and in the Centre for Women's Studies, Delhi) recounted her experience with disability. She knew of a girl who had a speech defect and physically she walked in a strange manner. The community kept chiding her. They would say,

Woh Tho Bechari Pagal hai ... (in the Hindi language it meant) ... this poor girl is mad. Most people will say we have been blighted ... they would do jharpukh (exorcism) and what not ... when the girl has an epileptic fit ... there would be this awful and very cruel form of trying to say that bhoot char gaya (in the Hindi language translated this means that she has an evil spirit within her).

She strongly felt that when one was talking about a child who was from the scheduled caste, who was poor *and* disabled, one was adding an extra disability, so that child would have to tackle three disabilities ... poverty, scheduled caste, disability. Then one would have to have '*a policy which was extra sensitive to*

reaching out to these kind of children.' Dr. Chitra Naik, Adviser to the Planning Commission on Education and Welfare reported:

They are just written off. Sometimes the mentally handicapped child is called mad, because they don't know how to classify the child; the physically handicapped are supposed to be useless human beings, so they are discarded and their parents feel they must have done something wrong in their last lives so this kind of child was born to them and therefore there's a kind of dislike of the child, even a hatred of the child, and these children are rejected.

She went on to explain that they are 'generally either concealed or not referred to at all.' The socio-cultural framework in which such an attitude was based could have affected the civil servants.

Discussing this cultural stigma and how it becomes ingrained, even in little children, Professor Kumar felt that it emerged out of the Indian scriptures, culture, books, kathas, and the folklores. According to him the cultural stratification existing within the Indian society would enhance rather than detract from the labelling.

The stigma on the part of other societal members, no matter how hard you and I may try ... that stigma is there, if the child is limping, the parents, teachers, management, principal, they may try hard to educate other children ... but the other children ... they say,* KANA, LANGDA, BEHRA, they cannot stop... (* These terms in the Hindi language meant blind, lame, deaf, respectively).

This meant that people suffered from a dominant cultural mind set. Rightly or wrongly, according to him, the attitudes in a society were not determined by logic, they would be dominated by years of stereotyping that may have taken place. Guilt, stigma, taboo were concepts reported by the respondents frequently and which came up in sixty-five per cent of the text units.

The group were divided in their views about whether policy-makers would be affected by this kind of a cultural framework of opinion that existed. Some believed that policy-makers were not touched by this, majority believed that policy makers were a reflection of the environment in which they functioned, and though they may not directly say so, their beliefs would be reflected in their work.

A social approach to the problem was suggested. Dr Tandon strongly believed that no social sector work could work without a social component, that work in this area could not be done with a bureaucratic approach. According to his definition:

A social approach means humility,
attitude of service, compassion.

Nani Palkhivala felt that it would be difficult to change people's attitude,

It is a mindset that has come down for
centuries and the policy makers are a part
of the Indian value system.

Rajmohan Gandhi from the Centre for Policy Research felt,

I think gargantuan problems are there, but
possibly some kind of unrecognised,
unadmitted attitude of stigma or whatever,
and a lack of political mobilisation - those
might be the reasons.

Most felt that an invisible force underpinned the marginalisation. This could be the cultural entrenchment which was a part of the value system in the sub-continent.

The seriously negative and pejorative
attitude in India towards disability is a
stark reality which one cannot ignore
(Javed Abidi).

However, the group was divided about the fact that such faulty beliefs, would have been a factor in holding back services for the disabled.

Policy makers may have a lurking belief
in the past deeds theory but there are other
factors that have affected the
marginalisation.

Dr Armaity Desai (Chairman University Grants Commission) argued that,

The Government gave precedence to poverty alleviation, illiteracy, and family planning. Many groups including the ageing population were neglected; scarce resources caused pressure on the policy makers to by-pass issues, more so if the issue lacked political pressure; and disability is one such issue (Dr. Desai UGC).

The indicators in the area of policy issues were:

- Ambiguity
- Contradictions
- A lack of explicit policy
- A lack of clarity
- A lack of convergence.
- A lack of political pressure.
- A policy of non decision-making

Sixty-five percent of text units in the Nud.list Analysis record the lack of clear direction and the lack of policy in this area.

8.5.8 Depoliticisation

The NGOs themselves had not put any pressure in this area. Dr. Verma, ex Director of the Rehabilitation Unit of the prestigious Medical Institute called the All India Institute of Medical Sciences in Delhi, talked of the confusion and the lack of conviction on this subject which professionals themselves had generated ²⁵. During his Directorship he had been asked by the Ministry of Welfare to convene a meeting of professionals and he said,

²⁵ Dr. Verma an expert in the field of rehabilitation in India for three decades had joined the interview that took place with Dr. B.N. Tandon.

Some of the associations want special schools for the disabled to continue, others want integrated education ... but this has been going on for a long time and they have not come to a compromise.

What is needed? The Ministry of Welfare asked me to head a discussion group formed to reconcile the differences between special educationists and educationists interested in integration ... and they were not ready to compromise. The associations representing different disabilities did not want integrated education: they wanted special schools.

The professionals themselves had not had a debate or discourse on the subject of integrating disabled children within existing resources and were clearly divided about this. The NGOs had not put any pressure in this area. Many preferred segregated services and were not willing to give up their bases. The Ministry had no department dealing with special education. The general perspective was that the disabled child had special needs and needed qualified professionals who were technically equipped to take care of the child with disability. According to the special education was a complex issue: it needed resources, organisation and many more forms of input. The technical perspective of the disabled child and the financial resources needed to attend to their needs was brought up frequently. Dr Chitra Naik, a key figure to have promoted the cause of Education and who was Advisor, Education and Welfare to the Planning Commission saw the management of disability as a medical model with a technical perspective and summed up what most respondents felt.

You see these children require medical care also, medical examination, medical care, some of the blind children or children with weak eyesight require nutrition perhaps, so there are various things. And now we are thinking of conducting rural surveys for these children because we find that they are not even identified.

Discussing the wider issue, Javed Abidi (disabled activist and economist) said,

I'm quite firm in my opinion that as far as disability is concerned it's not on the national agenda of this country. If you look at the national agenda you'll see a number of things: you'll see women's issues, poverty, now environment ... but disability is really not on the national agenda. Our nation's policy makers, our nation's politicians are not concerned about disability.

A matter of seva or charity: the NGO factor

Anil Bordia discussed the approach to the work and mentioned that in his readings of some of the Indian leaders who spoke about education and Gandhian concepts of basic education, there were 'very very few references to disability in all those programme' ... Gandhi did write at several places that even more than ordinary children disabled children needed to be served ... 'and serving the disabled child is the most important service'. The approach for many NGOs, he explained was still one of seva and charity.

It is like a religious thing, it is seva (service), welfare, dharma (Religion), the do good attitude ... feed them like leprosy... for years and years in this country it has been treated as welfare, charity you know philanthropy ... its only in recent years that people have started to take a sensible attitude towards leprosy... (Bordia),

The NGOs had concentrated on service delivery and provided some excellent services to fill the gap. However, it was a welfareist and a charity approach that had dominated. Javed Abidi mentioned that a closer look at the Indian NGOs in the disability sector indicated that,

... ninety-nine percent of them were providing some kind of a service. It could be special education, it could be rehabilitation, distribution of aids and appliances; but they have not worked in

areas of advocacy and equalisation of opportunities. This has contributed to the lack of a unified political statement or plan of action, resulting in a lack of political lobby and a disempowerment of the group (Abidi)

The Persons with Disability Act (1994) which had been recently passed was lauded by all. From 1994, after the passing of the Bill, advocacy groups led by disabled activists had been formed and for the first time the rights discourse entered the public arena.

I am not saying that before 1994 things were not happening. Things happened in the 70s also and the 80s but they were all fragmented, spurt of the moment kind of thing and very fragmented (Abidi).

Clearly the Persons with Disability Act (1994), had been a landmark in the lives of disabled people, establishing some kind of a rights issue after years of marginalisation. However, there appeared to be two schools of thinking in the debate; one that believed that one could not do both, deliver services, as well as, advocate for rights. It was not possible for NGOs taking grants from the Government to have a rights approach, as by doing this their power bases and their very survival were in question. Directly or indirectly one was dependent on the Government; directly through the grants and indirectly for various permissions, certificates, approvals and clearances. According to Javed Abidi, 'people were reluctant to take on the Government in case they were harmed'.

I strongly disagree with this kind of a stand. If you look at the women's movement, the environment movement, we have to rise above that kind of attitude (Abidi).

The following findings about the NGOs emerged

- excellent services
- micro not macro
- fragmented

- welfareist vs rights approach
- specialised
- depoliticised

The other aspect that emerged was that NGOs may have produced 'centres of excellence' but they had failed to focus on policy and the macro level, thus depoliticising the issue. NGOs receiving grants remained close to Government to serve their own organisation's interests.

I think the largest effort systematically and scientifically been made has been the Spastics Society, and now it's everywhere ... however, you have institutions for blind children, the hearing-impaired ... in all these institutions you do have children with disability but treated as a separate category. These children need to be identified first of all as a whole, this needs to be analysed recording the levels of disability and then they need to be put with other children ... I think this is something which is still left to be done (Anil Bordia).

Several informants mentioned that cross-disability consciousness and awareness was totally missing, and that the NGOs in the disability group remained fragmented and divided, each organisation geared to their own vested interests in serving their families with the different types of handicap. They were not unified with a common purpose,

More than any thing else there is a need for a Core group, probably a kind of a nodal agency. I hate nodal agencies because I think they perpetuate all forms of patronage, but in this case let's put it this way: you are only making a beginning today at the turn of the century. Whereas we have been around for the last 70 years ... right? ... Yes ... In fact I should look at it more positively, and say that it is indeed reassuring that people from these disabilities have managed to set up their

own groups ... it must be very difficult
(Bika Karlekar Sociologist).

Javed Abidi was strong in his accusation of the NGOs for not using disabled people in their organisations in management or policy-making positions: policy was still being guided by non-disabled persons. The point made was that persons with disabilities had to be involved in policy making in a proactive manner. If this is not done it could lead to the disempowerment discourse.

NGOs were all very, very loose and very fragmented. Very compartmentalised and what our experience in a very small way has been, that when it's a very large issue like the Disability Act, for example was one time, when a lot of people came together, because they could identify with it and there was this one large, identifiable, achievable goal. But when that identifiable achievable goal was not there, then they lost focus. Then they cannot understand why they are together, which is to my mind very wrong and very foolish, and that's being shortsighted because goals are not always visible.
(Abidi).

Advocacy: a rights issue

It had to be a rights issue, said some of the respondents. Another point made was that disabled activists need to come up on their own 'to the extent of being aggressive and shameless'. This had begun to happen although in the nascent stages, disabled men and women in various parts of the country were coming together. Activist Javed Abidi felt that it was important to move away from the charity approach to the rights model.

Without the rights approach, policy will not be sorted out.

He felt,

Unless you make a noise, you point out things that are wrong, policy will not happen. This is what has happened. We just kept quiet so they kept quiet. So it is

very closely linked. And secondly it will take time Ten years on the optimistic side, Twenty-five years on the pessimistic side. There should be debate; optimists will remain optimists and pessimists will remain pessimists.

May be twenty-five years from now we won't need a Welfare Ministry ... may be even in ten years from now the Welfare Ministry will not be needed. Ministries of Railway, Education, Aviation, Labour have cells dealing with problems of the disabled today, so we won't need a Welfare Ministry and that would be the greatest thing (Abidi).

Nani Palkhivala, too stressed the rights approach. According to him, the issue that had to be addressed could not be addressed with a plan or policy alone. Provisions need to be established as a matter of right. Of course, there had to be policy and provisions 'they should have this obviously'. Nevertheless, the question of how to establish this as a matter of right had to be done.

What has now begun to happen in Britain and started to happen many years ago in the United States:

You have to go to a court of law and establish the right (Palkhivala).

8.5.9 Left out of the Census of India

The most crucial finding of all that came through, was that to this day the Census of India did not include disabled children. A strong factor impeding the development of services is 'that there is 'no information about where these children are ... their location... no clear data.' A real problem for the exclusion mentioned was the lack of proper identification and definition. They were an invisible and inconspicuous group.

The surveys being done regularly by primary teachers as part of universalising education programme did not include the handicapped child as part of the programme of EFA. Under the Compulsory Primary Education Acts in the States, there were provisos that every child had to be enrolled and in some cases there were penalties for

parents also if they did not enrol their school age children. (Although it was difficult to implement this. But in the provisos parents could be questioned if they did not send their child). Teachers would visit villages and households to conduct door to door surveys, and children who were five plus and eligible for admission would have their names put down as eligible for formal school. Lists were then prepared and parents were persuaded to send their children to school. *The disabled child was not ever counted.*

Anil Bordia (Ex-Education Secretary said)

Several other kids were accounted for, but I don't think this was done for children with disability. I am not able to recall when a proper study was made.

What emerged was that no clear data, no stratified sample about age groups and locations was available about the disabled groups. Policy-makers did not know where they were.

Professor Verghese (Senior Academic and Researcher from the National Institute of Educational Planning) said,

One part of the problem is that there is no clear data about them. The problem could be solved if we had reliable information about them regarding residence. Location of disabled children in the villages could be spread out in a village. You cannot talk about a separate school specifically and separately for these children as they are so spread out ... so that is one type of a problem (Verghese).

Again,

we cannot geographically start a special school as we cannot locate the children; we do not have any clear data about their incidence and prevalence; that is if one was taking a decision to have separate schools for them.

However, he went on to explain that special schools were impossible to create in the rural areas as disabled children were so scattered.

Dr. Pradip Roy (Senior Researcher and writer from the Indian Council of Social Development) confirmed that in studies and surveys of the ICDS the disabled were not included. Every anganwadi worker along with the the helpers was also supposed to make a complete survey of children who were in the age group of two to five or six years. Disabled children were not included.

The explanation for this was:

I think it is, because the focus for the ICDS was initially in the rural areas where they don't have the medical back up to do very much about the disabled child.

It was confirmed by four following organisations listed below dealing with the ICDS that the disabled child was not included in their research. They were:

- The Indian Council of Social Development,
- The Central Technical Cell of the ICDS,
- The National Institute of Public Co-operation and Child Development,
- the National Council of Educational Research and Training,

The house to house survey being done and the monitoring of immunisations were separate evaluations done through medical colleges. None of these surveys mentions the handicapped child. The reason given was that definitions had not yet been clearly worked out, thus all children with disability had been left out of surveys.

A conservative estimate of those affected by disability is approximately five percent of the population or 45 million people (NSSO Survey 1991). This was a figure that the Government had estimated after the National Sample Survey Organisation (NSSO) was commissioned by the Ministry of Welfare to conduct

special surveys in 1981 and in 1991. Lok Jumbish ²⁶, a voluntary organisation working in the rural areas confirmed the rough statistical data of 3 to 4 percent disabled. However, from the socio-political point of view, although a huge number it is considered a minority group and according to one of the respondents '*an invisible minority, not seen not heard*' (Abidi, disabled activist).

Political Wilderness

The message that emerged was that the Government of India today had neither the political will nor the prioritisation of resources to bring justice as far as the rights of the disabled were concerned.

And how, can we ever progress when we are talking about such a vast number of the population being left behind (Abidi).

According to the Nud.ist analysis ninety per cent of the text units recorded the invisibility factor as a cause of the marginalisation from services. It was reported that

I think the Government does not feel strongly about this group because there is no pressure, there are not large enough numbers of people, the visibility is not so strong and with all other things having priority like poverty, illiteracy they begin to take the first precedence other things follow (Dr. Desai UGC).

One has to come to terms of recognition of special needs, and then how to integrate these children into the system

Policy doesn't get implemented into something tangible... operationalisation is required (Armaity Desai, UGC).

The whole issue was lost in a 'political wilderness'. Nani Palkhivala, passionately reiterated that nothing could be achieved

²⁶ Lok Jumbish means 'people's movement'. It was launched by Anil Bordia, Ex-Secretary Education, after he retired from the Government in the early 90s and deals with primary and pre-school education which includes disabled children in the districts and villages of Rajasthan, a state in India.

without political intervention and pressure because according to him 'nobody cares a damn for your handicapped people'.

And again,

There can be no two ways of thinking about this. State will do nothing they will only do if there is political pressure.

The handicapped are being denied their rights in the country. The only way is political pressure.

The handicapped do you think they have any political lobby? Not one percent.

8.5.10 Invisibility Factor

Frequent questions asked and statements made were ... *'we don't even know the number of disabled in this country'*... *'We haven't had a proper survey, our entire census figures are completely insensitive as far as the disabled are concerned. What do you mean by disabled?'*

Statements such as *'being considered a non person'* ... *'did not come into the purview of the masses'*... *'did not figure at all'* reinforced the invisibility factor. This seemed to be what a respondent said was a major factor in contributing to the situation of isolation where the child *is* ... and not where he or she *should be*', said one of the academics.

I think the issue of inclusive education should be discussed; people must realise the need for inclusion ...the problem is, I think there is so little mileage to disability (Bika Karlekar).

'There are so many categories of disabled. Where are the definitions?' Brinda Karat (Political Activist and General Secretary of the Federation for Women in India) summed up what most of the respondents felt:

You have to get Government to change its policy as far as the categories are

concerned. First change the policy as far as categories are concerned, and then we go into the details of specific. At present *there is no Policy*.

According to her, if one looked at another policy... the Health Policy for instance, specific problems, which disabled people, face as far as their health issues are concerned; this too had not been addressed.

Therefore I would say the Government approach towards ICDS is very much part of a common pattern of the Government of India vis-a-vis the disabled, and therefore to change the approach of the Government to ICDS you have to go to the roots of the issue which is question the very basis and framework of Government Policy towards the Disabled.

What came across strongly from the investigation was that the exclusion of disabled children from Government's anganwadis in Dharavi was symptomatic of the wider malaise that existed in India. It was not the question of ICDS leaving out disability that was answered by the study; it was a wider question of Government Policy leaving out disability from the national policy agenda, which had been answered.

Summary

This chapter has recorded the investigation done with the policy-makers with the aim of trying to get an insight into what the larger issues have been in contributing to the non-inclusion of disabled children from the services of the ICDS. The policy-makers were clear that the disability issue had not been a part of the political agenda during the period of ICDS policy formulation. Therefore, when the objectives and priorities for the ICDS programme were being worked out this issue did not come up on to the policy agenda and resource allocations were not done for disabled children. The wider question of factors influencing the policy-makers also came up. The findings showed that it was not just the ICDS policy that had left out disabled children, but underpinning this was really a broader ethos of marginalisation that is taking place

from the nation's entire policy for the vulnerable sections of the country. The ICDS policy is embedded within a larger conceptual confusion about the needs of disabled children and the responsibility of the State. The Government's conceptual confusion about rehabilitation rather than education as meeting the needs of disabled children has come in the way of clear policy-making. This is why disabled children were the responsibility of the Ministry of Welfare, which did not have education as part of their agenda. The reliance on NGOs to provide this had contributed to the confused objectives and priorities for this group. The non-government sector had contributed excellent services, some of them, but had not worked in the area of rights, there not being enough services for disabled children. This had contributed to a lack of advocacy, thus contributing to a depoliticisation of the situation. Another factor that had contributed to the marginalisation was the fact that the disabled group was a politically weak group, weakest among the weaker sections consisting of the scheduled caste and the women's group. The other finding that had affected the situation was the ideological value system. A negative and pejorative attitude prevailed in the sub-continent that kept them apart from the rest of society through socially constructed barriers. Another finding was that the disabled were not a part of the Census of India, as proper definitions had not been worked out, nor were they a part of the survey that took place for universalising education, nor were they a part of the ICDS research surveys. Therefore a major finding was that they remained invisible and their marginalisation was widespread. The Ministry of Welfare as the nodal agency responsible had failed to prevent this widespread marginalisation from happening. Today a lack of clear-cut policy formulation prevented disabled children from getting access to existing provisions and services available to other vulnerable groups.

PART SIX

THE ANALYTICAL FRAMEWORK

9 ANALYSES AND DISCUSSION

Introduction

Chapter 9 analyses and synthesises the principal findings that emerge from the policy-makers and the focus groups in response to the research question detailed in Chapter 1. The thesis examined the reasons for the non-inclusion of disabled children from the ICDS policy and practice, and investigated the wider historical and political issues, the social structures and the socio-cultural value system within which the ICDS policy may have got embedded. Chapters 7 and 8 reported the findings of the data collection from the focus groups on the ground level and the policy-makers at the top level; this chapter analyses the responses of both groups in the community and at the top level, as factors which could have contributed to the non-inclusion. The chapter concludes with a synthesis of the analyses of the principal issues, which emerges from the study in terms of a policy discourse.

9.1 The Focus Groups with the community

In Dharavi, we find people locked in an acutely impoverished situation of poverty without access to basic amenities such as nutrition, health care and education. Their life was one of utter squalor without safe drinking water, electricity, decent sanitation resulting in serious health hazards. These difficulties were further compounded in some families by the fact that they had a handicapped child.

From the focus group discussions the following factors emerged:

a) A lack of policy directive from the top

The study confirmed that the Government's anganwadis did not include disabled children in the local nurseries, which they were running in Dharavi. The disabled child did not receive basic nutritional supplements either, as this was meant for those children who were registered in the programme.

(b) NGO dependency: a technical perspective to the problem

The pattern of NGOs setting up services for the education of disabled children all over the country was found to be very much a reality in Dharavi. Both groups of parents, those who were receiving services and those who were not, were of the opinion that their child needed a 'special' school and therefore did not go to the anganwadis either. Here in the slums too amongst a semi-literate population, the technical perspective and a specialisation needed for their disabled child came through. Several NGOs had provided services here and the parents did not find the need to send their child to the Government's anganwadis (Appendix 8 shows NGOs working with disabled children in Dharavi). The ICDS workers also felt that the disabled child needed a special school; the technical and a specialised way of handling disabled children was best for 'these children' dominated thinking. The lack of awareness about their children drove some of the parents to believe in exorcism, witchcraft. The study revealed that the parents did not go to the local anganwadis as there were barriers existing in their own minds that this was not a service for them and that their child could not go for these services. As was mentioned by one of the respondents it was 'these social barriers within the family which were a factor contributing to a social exclusion taking place within the community'.

Some of the parents had taken their disabled child but had been told that this service was not for them. Most of the ones attending the services laid on by NGOs did not find the need to go to the anganwadis being very satisfied with what they were receiving. This resulted in a lack of pressure on the anganwadis to admit disabled children.

c) A lack of implementing mechanism

An investigation of the documents relating to the syllabus confirmed the lack of a disability component, in the training programmes of both the anganwadi workers and the supervisors. The ICDS personnel, consisting of the auxilliary nurses, the graduate supervisors, the anganwadi workers, confirmed that their training did not include information on how to deal with the disabled child. The 'front liners of the delivery service' (Lipsky 1980) or the 'street level bureaucrats' who usually have a high level of autonomy and discretionary powers in rationing services were left to deal with the issue of the disabled child without any training and without a clear directive to include. The supervisors mentioned that they were not unwilling 'to take such a child but needed the directive to do so, as well as the necessary infra-structural support'. They also mentioned the lack of infrastructural support and the lack of training. They mentioned during the discussions that they were supposed only to carry out 'what the state directed them to'.

Unless the law contains clear directives about the inclusion of disabled children; and unless this is backed up with implementation strategies of how to manage them, distortion of policy will continue to take place. It would be difficult to legitimate services for disabled children without a policy of positive discrimination which states disabled children are to be included into the existing programmes. This also has to have the resources needed to implement such a directive. The inclusion of disabled children into the programme cannot be left in an ambivalent vague manner to the discretion of the street level bureaucrat in a situation where there is such a high demand on the service, and where such negative attitudes prevail.

d) Political weakness and powerlessness

The focus group discussions revealed that the families were overwhelmed by their poverty. They were caught in a survival culture where they were dependent on the Government for their huts and the space they were occupying. Their powerlessness (Lukes 1974) did not allow them to question the Government, so they preferred to remain silent on the issue. Since they had overwhelming problems of employment and mere survival, the progress of their disabled child was least of their worries. They did

not seek any change in their situation as they were engulfed in a sense of fatalism and resignation, accepting their lives unquestioningly.

Although all groups came under the socially disadvantaged category, even within this underclass, the families with disabled children were not eligible for the provisions being given. The families were not conscious of the services as being a matter of their right to receive, nor were they politically conscious. They had no idea who their local councillor or member of the state assembly (local parliament) was. The political weakness again could very well be due to their dependency on the Government. The Government on grounds of encroachment often broke down huts. If they were thrown out of Dharavi, it would spell economic disaster for them. There were no avenues for them to air their grievances and gain redress, having no access to the media, newspapers or T.V. They were not willing to question the Government either when their very survival was in their hands, so they preferred to remain voiceless and invisible.

e) Negative attitudes causing socio-cultural barriers

The study showed that extreme prejudice and negative attitudes towards disability prevailed in the slums of Dharavi. Parents were caught up in faulty misconceptions about their child. They believed that they were to be blamed for their child, it was their 'individual tragedy' (Oliver 1988) and nobody should be asked to carry 'their burden'. 'Such children' (as one of the fathers said) were looked upon as 'deviants to be hidden away'.

Mothers were the main carers and were usually blamed for having such a child. The study indicated an anti-female bias to disability. Having a disabled child in the family was something unspeakable, something to be ashamed of and the daughters-in-law were invariably held responsible for 'this calamity and curse'.

What came up was that the person who was disabled was a burden and a liability in this culture and it was a taboo and a stigma to have a disabled child. The families felt isolated and stigmatised.

Cultural beliefs are barriers to developing change (Ingstad and Whyte 1996). Societal beliefs affect the whole family. Eayres (1993) argues that,

It is a well-accepted fact, that labels have a potentially damaging effect. Labelling can cause people to act the way they are expected to. If they were supposed to be mad or ineducable they would act this way which would have a detrimental effect on their development and growth (Eayrs et al, 1993:111).

The study showed up the cultural constructs of disability; the cultural patterns of meaning in which 'disabled families' see themselves in the Indian situation among the weaker sections; the way the community labels, categorises and then socially excludes certain people who do not fit the norm.

f) Other contributory factors leading to isolation

Another finding was the lack of socialisation. Mothers did not have a park or playground to take their child to. Travelling on public transport by bus and carrying their child was another difficulty reported. They could not afford the exorbitant taxi fares either therefore mother and child spent all their time within the constraints of their hut. It appeared that this is why the family avoided going out even on holidays to visit their relatives.

The key findings in Dharavi were that the families with disabled children received no services or facilities from the Government for their disabled child, that faulty attitudinal barrier of superstition, witchcraft, exorcism prevailed. The stigmatised family withdrew from society, into a shell of separateness, perpetuating a practice of isolation themselves and believing whatever society wanted them to believe as the truth. In short, they appeared a victim of cultural discrimination, a powerless group whose voices would not be heard in the channels of policy-making agendas (Bachrach and Baratz 1970; Lukes 1974).

It was a vicious circle perpetuating this line of thinking ...

- the NGOs, finding no services for the families and children, went ahead and provided them, with funds raised from national and international sources but this only created a situation where
- the families were not aware that they could receive facilities if they demanded them, and therefore did not put any pressure on the Government for change
- the NGOs were busy with the enormous demands of a huge population without services; they carried on with service delivery unquestioningly, guarding their individual interests and bases, and
- since no government works without pressure, the state was absolved of all responsibility.

9.2 The Policy-maker's Perspective.

a) A lack of policy directive from the top:

A conceptual fragmentation

From the semi-structured interviews with the policy-makers the following factors emerged:

In 1966, when the responsibility for the handicapped had been passed on to the Ministry of Social Welfare from the Ministry of Education, the focus shifted from education to rehabilitation. There was no plan of action formulated for educating disabled children or integrating them into existing services. Voluntary organisations were supposed to carry on the work of education. This was the first move in a conceptual fragmentation of the issue. The framework within which the disability group then got buried is a framework of rehabilitation and care, not education.

The pressing problems of the normal child's health and education, the pressure in achieving universal education, became Government's top priorities. The confusion in

conceptualising the needs of the normal child did not help in developing a cohesive coordinated service for them either. Instead of one agency dealing with the child and its diverse needs, we find the child has been 'dissected' into separate segments and its various needs distributed among separate Ministries. This conceptual confusion fragmented the services for children, be they disabled, socially disadvantaged, street children or children being used for work purposes as a few of the respondents mentioned.

Again the role of the Ministry of Welfare does not seem to be clear. The Ministry of Welfare is the nodal Ministry in charge of the disabled group, but the Joint Secretary mentioned that the Ministry's objectives 'were to rehabilitate not educate'; 'education was the responsibility of the Ministry of HRD'; her role as she understood it was 'to persuade' other concerned Ministries to action 'to include the disabled in their programmes'. Words such as 'persuade to take them' (them meaning disabled children) indicates a confusion and a lack of adherence to the principles of entitlement. Policies cannot be implemented by 'persuasion' alone; policy-making we have noted is a political activity, dealing with various groups with their vested interests competing over scarce resources. The Ministry is also not a high status one, and staff transfers to this Ministry are seen as a demotion by civil servants. Therefore, the issue of affirmative action about the rights of disabled children appears not to have come up at all. The disability issue is rooted within the charity and welfare framework and not within an equal opportunities one. The Government's messages are mixed and contradictory.

The Ministry's responsibility is mainly identification and rehabilitation, concerned with aids and appliances, vocational rehabilitation etc. The Ministry, at an enormous cost to the exchequer had developed four National Institutes. The agenda of these 'monolithic agencies' as they were called by one of the informants, is not to deliver services but conforming to general Government policy of identification and referral only. The main aim is to generate trained rehabilitation experts within a framework that is segregationary. The objectives of the National Institutes are in direct conflict with the Government's policy and high-budget programmes of integration that have been embarked on with World Bank support.

The central issue that emerges is a dualism in Government policy, a lack of clarity and direction, which has led to divergent ways of functioning. The lack of a conceptual framework of needs concerning the disabled child is the major weakness causing a lopsided foundation. In 1997, 50 years after Independence, we see that there is still no clarity in the policy formulation for this group. The Ministry of HRD continues to promote integration and the Ministry of Welfare continues its practice of special schools with no convergence taking place. This dichotomy between policy and practice came up frequently. Separate strands within the Government's practice have become perpetuated.

b) An NGO dependency and the technical perspective:

The climate in which the work for the disabled in India is done is still considered 'good' and 'humanitarian acts of seva or charity'. The belief that only special schools can handle the disabled child prevailed also amongst the policy-makers, as we found even in the community. Tomlinson (1982) argues that

Special education is permeated by an ideology of benevolent humanitarianism, which provides a moral framework within which professionals and practitioners work (Tomlinson 1982:5).

Professionals had introduced 'centres of excellence' into the country but work for the disabled had a technical mystique around it.

The humanitarian approach cannot be completely criticised. Caring for anybody is important for the development of any community. The values of compassion, care and sympathy that humanitarianism espouses are important to inculcate in any community. Important also for development are 'notions of duty and responsibilities' (Roaf and Bines 1987). This kind of culture has been set up in India by numerous people concerned with social change, intent on social reform and service to a much neglected segment of human beings. However, this kind of thinking has not helped to develop a rights or entitlements approach for disabled people. According to GOI statistics ninety-nine per cent of the services for disabled children were being

delivered through the voluntary sector (GOI 1994) and they were fundamentally engaged in the delivery of services.

In the absence of a positive contribution from Government, the NGO contribution was a critical one, nonetheless, overwhelmed by the demand on their services without analysing the implications of their actions on a macro level, the NGOs had perpetuated and unconsciously supported the 'charity and welfareist approach' rather than the rights approach.

Inadvertently they had taken the disability issue out of the public domain, nor helped to develop a state responsibility. The Government sustained this course of action as it suited Government's own agenda for the disabled group

c) A lack of implementation strategies leading to a lack of awareness

The language of special education remained technical and some informants called it esoteric, and said it was understood only by a small minority not by the general public. On a macro level none of the teacher training institutes had included the education of disabled children as a part of their syllabus. The civil servants mentioned that it was an 'area of darkness' for them as well.

d) The social construct of disability in India: a socio-cultural fragmentation

The policy-makers confirmed that there is a deep-rooted prejudice about disability, which needed to be addressed. They felt that on the whole the social construct was a negative and pejorative one. They felt that the kind of prejudicial thinking that prevailed was only amongst the semiliterate societies, and that this kind of stereotypical thinking would not have influenced them. However, there was a divided opinion about this; as some felt that policy-makers were a reflection of the society they came from, and the same entrenched negative kind of ideological bias would have affected their decision-making.

(e) The structural confusion

In the structural context, adjustments and inter-ministerial co-ordination between the two Ministries of Education and Welfare has not taken place. Both the Ministries of HRD and Welfare functioned in the same building. The Departments of WCD dealing with ICDS policy and practice as well as the other two departments dealing with integration also functioned in the same building. The DPEP and the IEDC had large budgets. It was reported that they were compartmentalised with a wall between them. They were not separated spatially, but ideological barriers kept them apart.

Many researchers have written about the inter-agency difficulties that can be a historical entrenchment and can impede progress. Welton and Evans (1986) see one of the major obstacles to a co-ordinated planning in delivery of service being,

Inherited division of welfare which a) establishes and maintains the statutory and administrative framework and b) creates, justifies and protects competing definitions of client needs and professional response (Welton and Evans 1986:218).

It could also be called 'a tunnel vision' (Barton and Landman 1993) when departments are geared to just the aims of their single department instead of functioning with a holistic approach. Although Barton and Landman (1993) argue in the following extract about a kind of tunnel vision which compartmentalises professional 'mentalities' in the context of the Warnock Report and difficulties of implementation that took place amongst the bureaucracy in the UK, it has some similarities to the Indian context.

This form of tunnel vision is a reflection of the compartmentalised mentalities related to professional interests which have historically informed much of the policy and practice within special education (Barton and Landman 1993:47).

A lack of convergence between the departments of DPEP, IEDC and WCD has led to confusion about their roles in promoting the ideology of equal opportunity. For

ICDS to integrate disabled children, the Ministry of HRD would be the main vehicle to carry through this change, in keeping with the overall goal of Government commitment to universalise education. This has not happened.

The Ministry not having a separate department on pre-school education came up several times, as having led to a lack of focus on the critical pre-school period which involved the ICDS service. It could be argued that EFA was only intended for the age group of 6-14 and that pre-school was an area which did not come within this purview. However, there is enough evidence to indicate that the pre-school years are critical and those who have had pre-schooling have a longer chance of sustaining education than those who do not (Sylva and Lunt 1982; Saraswathi 1993; Myers 1992), and that this is equally true for disabled children (Guralnick 1976; Bricker 1979; Bruininck 1985). It is also evident that India appreciates the importance of the pre-school period and therefore introduced the ICDS programme. Informants felt that pre-school disabled children should not lose out because they were not under the Ministry of Education. Their special needs should be met and the Ministry of Welfare was not meeting this. According to some of the respondents, it was critical that responsibility for the disabled child was placed back within the purview of the Ministry of HRD, and a coherent policy for their education, formulated

The respondents reported at some length about the confusion of roles, unclarity of objectives, and a lack of cohesion in the government's policies being caused by the two ministries; and the fact that structural adjustment to the philosophy of integration has not taken place within Government's own machinery indicating serious infrastructural weaknesses. A silent war and a struggle for power among the civil servants, appears to be happening in the corridors of the two ministries entrusted with the responsibility of children with disability ²⁷ perhaps similar to 'endemic struggles' and 'internecine conflicts within small and large bureaucracies' as reported by Bowe et al (1992): 'micro politics' that exist in the absence of proper definition of issues, of roles, of policy and practice. Shedding old traditional 'legacies of inheritance' as Whitmore (1984) reports can also create difficulties. Historically, the Ministry of

²⁷ A high proportion of text units in the Nud.ist Analysis indicates this lack of co-ordinated approach to the problem as one of the major reasons for failure on the ground level

Welfare inherited the charity approach to the problem when the two ministries were divided.

f) Other contributory factors

The Invisibility Factor: 'just does not figure'

A critical revelation that came up was that the disabled child was not included in the National Census Studies. There were volumes of research done on child surveys, but disabled children were not included in any of these surveys either.

Attempts to define 'disabled' had run into conceptual problems of the most fundamental sort all over the industrialised countries. Differing definitions and terminologies made it a highly complicated problem.

Tomlinson (1982) suggests that,

It is interesting to note that each survey during the twentieth century has progressively discovered more and more children with defects, handicaps or special needs, and it hardly needs to be pointed out that numbers depend on the definition of the category (Tomlinson 1982: 15).

As Rutter et al (1970) noted,

How many handicapped children one finds in a survey will depend largely on the criteria of handicap adopted (Rutter et al 1970: cited in Tomlinson 1982: 15).

Hahn (1985) argues that,

The definition of disability, is fundamentally a policy question (Hahn 1985:134).

It was also confirmed by the Women's Groups that in the Indian situation until recently, the girl child was not acknowledged in the Census Studies and it was only

after lobbying and negotiating, that questions sensitive to picking up the number of girls in India were inserted.

Besides the issues mentioned a question of invisibility emerged as a significant finding, a kind of tacit concealment that ignored the existence of this underclass of people: ‘creating silences on the matter which suited people wielding power and control and producing an inescapable ambiguity’ (Knight 1990).

9.3 A synthesis of the findings

This was a top-down bottom-up research, where the policy-makers at the top level were interviewed as well as the recipients, the non-recipients and the administrators of the ICDS practice. Although two very disparate groups participated, the policy-makers being highly-educated, well-placed, articulate, powerful and influential, the other, an antithesis, being powerless, semi-literate, socially disadvantaged, their responses on the subject were similar and inter-related in the major issues that came up in many ways. Their language remained different, the group at the top being articulate had more to say on the wider issues that may have come in the way of the marginalisation. They were more detached than the group at the bottom level not being personally affected. The group in the community being seriously affected by the local conditions around them, were passionate and at times bitter while discussing the issues.

From the policy-makers’ discussions on top emerged the following issues:

- a) A conceptual confusion about the issue; structural incoordination leading to unclarity of policy objectives and policy directives from the top;
- b) An NGO dependency on professionals with a technical perspective leading to a lack of awareness, knowledge, information on disability;
- c) A lack of implementation strategies leading to a lack of awareness, knowledge, information on disability;

- d) A cultural entrenchment;
- e) Depoliticisation;
- f) Other contributory factors;

From the focus group discussions at the bottom level emerged:

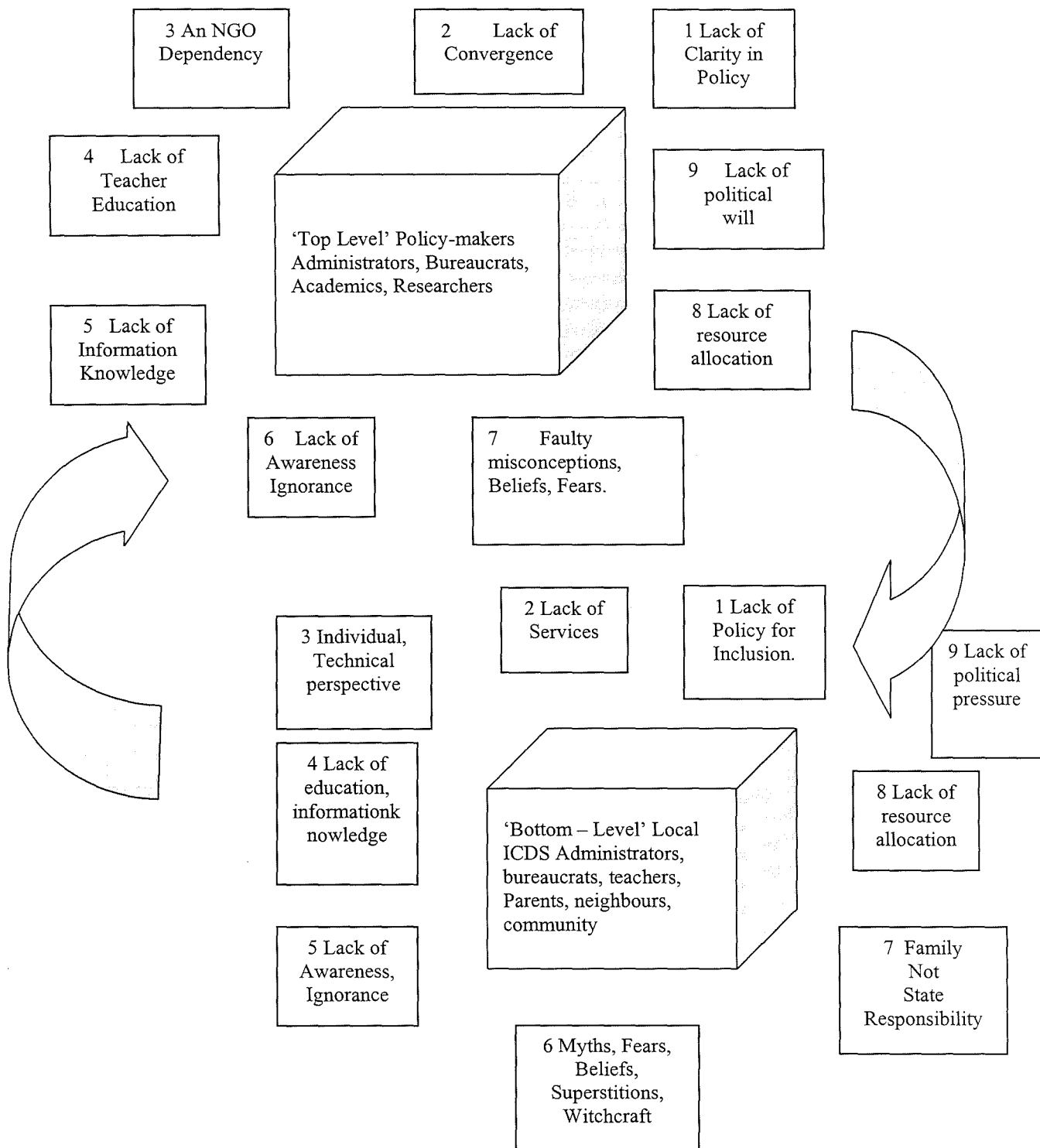
- a) An absence of policy directive from the top resulting in a lack of services.
- b) An NGO dependency with a technical perspective to the problem.
- c) A lack of awareness about the whole issue of disability.
- d) Political weakness and powerlessness;
- e) Negative attitudes and socio-cultural barriers leading to social exclusion.
- f) Other contributory factors.

The outcome of the findings and the common linkages that emerged is illustrated in Figure 9 overleaf. This section blends these issues and concludes the analyses.

In terms of a policy discourse: the policy formulation stage.

On a broader level in the critical formulation stage the issue was not clearly defined. This happened when the Ministry of Education was being bifurcated and the Ministry of Welfare being created. When the disabled group was being transferred from the Ministry of Education (now HRD) to that of Welfare, During the policy formulation stages the issue of education lost focus. Inappropriate conceptualisation about the needs of the disabled child took place. The objectives of the Ministry of Welfare became to 'rehabilitate' rather than to 'educate'. The Ministry was meant to act 'as a nodal agency in co-ordinating services for the disabled'. A lack of specifying the target of educating disabled children resulted in the absence of setting up the

Figure 9: A Top-Down Bottom-Up Synthesis



the mechanism for implementation. Consequently, a lack of accountability about the issue of educating the disabled child also prevails. The Ministry of Welfare functions without education as a service target, which absolves them of the responsibility for educating this child; the Ministry of HRD functions without a special education department, which absolves them of responsibility of taking on board the needs of this child. Consciously or unconsciously barriers appear to have got reinforced and we see what Schattschneider (1960) terms as a 'mobilisation of bias' happening within the Ministries where this group's educational needs fall into a pattern of non-decision making and inaction causing a failure in policy. This is where in wider terms the lack of a conceptual framework for the disabled child's needs emerge as a key indicator of contributing to a lack of issue definition.

Again, due to this overall lack of a conceptual framework, the issue of disabled children 'did not figure' in any of the discussions during the ICDS policy formulation stages at the top-level. The end result (as we see on the bottom-level in Dharavi) is that policy is lopsided giving no direction and failing to include disabled children in the programme.

The weaknesses in the implementing mechanism both at the top and the bottom level follow. We find that the objectives of all staff training courses conducted by the Ministry of Welfare's National Institutes is not education and management of disabled children but 'identification and referrals' only. Similarly at the bottom level, we find the goal of 'identifying and referring' being carried on in the ICDS training syllabus for the anganwadi workers and the supervisors.

The findings indicate that a lack of knowledge on the issue permeates from top to bottom. On a still wider level on top Government teacher-training organisation such as NCTE, NCERT, DPEP, in which around five million teachers in the country are being trained do not have a disability component in their syllabi.²⁸ DPEP has recently begun including the disability component but the practice is ad hoc not uniform or large-scale. The Director of NCERT said, 'NCTE and DPEP have not dovetailed their activities' or 'They have not come to grips with this issue'. The Chairperson of the

²⁸ Government of India 1997 Annual report states a total of 43,98,421 teachers: primary being 29,05,170; secondary being 14,93,251.

University Grants Commission, also confirmed that the disability component has not been introduced into the teacher-training courses in most of the Universities; nor was it a part of many of the Child Development Departments in the Universities, only a handful of departments having introduced it within their colleges. Most of the teacher-training activities are being conducted by the voluntary sector on the micro level. At the bottom level, the supervisors and the anganwadi workers too mentioned the lack of training in this area and their inability to handle these children.

A lack of training of teachers in the field ensured a lack of information and knowledge on the subject. Tomlinson (1983) and other writers suggest that this kind of approach has added to the continuance of the practice of segregation (Tomlinson 1983; Fulcher 1989; Slee 1993). It has invariably been construed as being highly technical needing a specialisation. It has also been found to be the key factor in the medical paradigm of labels and categories continuing (Slee 1993:355).

We have noted how policy formulation sets the agenda for implementation to take place. We have also noted that policy-makers need to have clear definitions of the issues, the objectives and priorities. However, policy need not explicitly state the objectives. Policy can remain silent on certain issues; 'non decision-making' can take place (Bachrach and Baratz 1977). Analysing the documents that record the beginnings of the ICDS, such as the First Five Year Plan in 1975, we find that the reference to 'all needy children' does not expand to specify disabled children. In an anti-poverty programme, not all the recipients who are to benefit have been clearly spelt out. Policy remains silent in the matter. Neither the documents nor the literature detailing the objectives of the ICDS policy and practice nor the research carried out over the twenty years make any mention of disability. This is substantially borne out by the 'street level bureaucrat' (Lipsky 1980) theory in the field. It is common for the 'street level bureaucrats' to ration and modify goals, often distorting policy in face of heavy demand (Lipsky 1980). Here in Dharavi, in a situation of heavy demand, where we find that policy does not explicitly direct the inclusion of children with disabilities, it is much more likely that arbitrary decisions will take place, leaving the matter of the disabled child to discretion rather than entitlement.

The State's reliance on the voluntary sector for the provision of piecemeal services as we see in Dharavi too, put control into the hands of a powerful professional group. The NGOs remain fragmented due to various factors. A sense of insecurity about their funding position: a NGO/Government nexus since Government gives them the grants to continue their work: a high degree of competitiveness in building up and guarding their power bases: prevents the disability groups from coming together. Their policy objectives being mainly delivery of service each function in an individualised manner. The Government's concern in maintaining this situation is understandable, as it ensures less resource allocation for this group. The geographical logistics of the subcontinent and the expenditure incurred in travelling are barriers to frequent contact between the NGO groups. There is no cross-disability movement or one single Disability Federation involving all the NGOs dealing with different disabilities. The NGOs remain a fractured and divided group. The Government too has kept the situation fragmented by dealing with the problem not on a macro level, but in a micro piece-meal manner, keeping each individual NGO within their control.

The NGOs, as they increase their activities, increase their dependency on the Government; not having the rights approach to the issue either also contributes to the depoliticisation of the issue. Again, one could argue that NGOs were collaborating with the Government in producing much-needed services in a situation where there was none, that in the face of the pitiable situation that the families were facing in the country as we see in Dharavi, urgent action was needed and the NGOs acted in a manner that they knew best. However, the pressure on the state to include this child did not take place. The state's abrogation of responsibility and the passing of it to the NGO sector increased the political weakness of the disability group.

The belief that special schools are required for special children, is a thought that is reflected amongst the people in Dharavi. This belief is reinforced by the good work done by the NGOs in their area. Another belief emerging is that the families think of having a disabled child as their individual problem; the state means nothing to them. The thinking, that it is an individual personal tragedy, which the family has to bear

(Oliver 1990), again absolves the responsibility of the State and denies the families of the understanding that they too have rights.

A charitable and humanitarian approach to the problem emerges. The issue remains invisible removed from the public domain not figuring in any political manifesto of any of the political parties--a private problem for the families and the NGOs to deal with. The NGOs too have shaped this opinion over the years

The 'established bureaucracies' choose to remain equivocal letting the matter remain silent and concealed. It suits their budgetary distributions to let NGOs raise much needed resources for this clearly ambivalent area. Attitudes are difficult to overcome. The arithmetics of giving resources to those 'who showed the best and quickest results' certainly pervaded their thinking. It can be inferred that they had inadvertently discriminated against this group. It has been suggested that,

Discourse, procedure, and even sites may change but traditional ends are affected because of the resilience of ideologies of 'failure' and 'normality' and the established bureaucracies which sustain these understandings (Slee 1993:352).

Writers have argued that,

This resource driven analysis can de-problematise integration through the absence of an appreciation of the social construction of disability (Slee 1993:351).

A framework of chaos and confusion emerges from the top due to the lack of the issue remaining undefined. Ill-defined inappropriate conceptualisation of the needs of the disabled child leads to a lack of clarity, ambiguity, and a silence on the matter. An unclear focus, ambiguity and contradictions at the top-level of policy-making percolates down to the bottom causing distortion and confusion in the delivery of service.

9.4 Values

A socio-cultural fragmentation

A wider value system underlies policy discourses. There is no single answer for any culture nor is there a universal set of priorities (Ingstad and Whyte 1996). On a much wider level disability and its conceptualisation are reflections of a cultural and social construct. Here in Dharavi, we see an example of how the families saw having a disabled child as a question of an 'individual responsibility' and how the community's faulty negative attitudes reinforced it. The parents' battle for a day to day survival prevented them from thinking about the needs of their child with disability. Their life in the slums was to do with a survival culture; 'roti, kapda, aur makan' or 'food, clothes and shelter' these were the three necessities. Combined with this way of life was the fatalistic attitude of their cultural mind-set, where the belief was 'who can do anything?' 'It's my fate and I have to bear it' 'it's my fault' ... which made them voiceless ... an individual construct of a personal tragedy theory that has been written about by several writers. The families' views were shaped over the years They believed that their child needed a special type of care, which the anganwadis could not give. They also believed that their disabled child should not go to the same schools as normal children. The anganwadi was seen as existing for the benefit of the normal child. This kind of thinking had been exploited and allowed to continue

Oliver (1988) argues that the 'personal tragedy theory is the root cause of much of the social injustice experienced by people with disabilities' as it takes the matter away from the public domain to a private one (Oliver 1988), in this case an 'invisible' one. The attitude to the group is one of paternalism, charity and welfare. No Government works without pressure. Issues, if not brought up to the policy agenda, remain unchanged (Dye 1984). There is no pressure on the political system for change. The political system is not proactive and continues to rely on voluntary agencies. The issue is moved away from being a State responsibility absolving it of any accountability. This remains well-ingrained within the social structure. This is evident both at the top from the expectations of the policy-makers who talk about the

excellent work of the NGOs and at the bottom from the street level bureaucrats who talk about the need for special schools for 'these children'.

A mystification of the issue had contributed to this area being enveloped in a technical approach. Special education needed a language understood generally rather than limited to specialist groups. On a wider level training has not been initiated.

This leads one to contend that the Government has not addressed these problems to suit their own vision and value allocated to this group and that the professionals too have not analysed the implication of their work and kept it within narrow boundaries they had drawn for themselves. This leads one to further contend, that the policy-makers as well as the NGOs themselves, have been influenced by the general medical mould of disability -- a dysfunctioning individual either needing technical skills on the one hand or only familial love and compassion. Consequently, the state does not have a direct responsibility for disabled children. The state plays no part. This approach fits in with the priorities allocated by the Government. Although this may have not been deliberate they are contributing factors to the values allocated to this group. On the ground level this value allocation comes through. We find the families suffering from faulty misconceptions and beliefs, which seriously affects the mother and the child as they remain socially excluded and institutionally discriminated against.

Each society has its 'regimes of truth', the type of discourses it accepts and lets function as truth (Foucault 1974). The divisions of segregationist practices are carried through a means of institutional discrimination taking place from the early age of two, through the Government's apparatus. The state is the source and the apparatus through which power is organised. These 'regimes' are laid down and 'truth' operates; in Dharavi we find through social exclusion and marginalisation. Policy directs the street level practitioners to 'only identify and refer' disabled children to other organisations, preferably to 'special schools'. These 'dividing practices' (Foucault 1974:49) have been used to legitimise actions. The discourse of what constitutes normal and the norm gets internalised within a system (Foucault cited by Hunt and Wickham 1994:53)

The politics of disability

The powerlessness of the group under study is another key factor that has contributed to the silence on the matter. Even under the positive discrimination, anti-poverty programme, this group's entitlements are not considered. Although poverty and disadvantage could have been two reasons for including children with disability into the net of provisions, a third classification is made within this socially disadvantaged group and on the grounds of disability the children are divided into handicapped and normal. Political expediency demands that only the politically stronger group, amongst this underclass of people should be given provisions.

Bachrach and Baratz (1977) have argued that decision-making and non-decision making is a result of a 'mobilisation of bias' which involves the exploitation of certain conflicts and the suppression of others and gets embedded into the political system and subsystem.

Some issues are organised into politics
while others are organised out
(Schattschneider 1960:71).

In the functioning of the Indian Ministries of Education and Welfare, we see this bias coming through in the chaotic piecemeal provisions and the ambivalence of roles. 'Governmentality', argues Foucault (1974), another term, which is relevant to this discourse, constitutes modes of action in a way in which the conduct of individuals might be directed 'How things get done'. Parents were blamed for not availing themselves of the services. Their attitudes to their child needed changing. Parents, when questioned about why they did not attend the ICDS, mentioned that the local AWWs would not be able to manage their children, as the AWWs were not trained. Any practice faulty or otherwise, can be perpetuated by repetition over the years, until people have a mind set about it and they become passive actors in the plot.

It is through a repetition of normative
requirements that the normal is
constructed (Foucault 1974:50 cited in
Hunt and Wickham 1994).

The Conflict of Resources

Policy without funding is no policy at all. In most countries funding constraints for disabled children are a major issue, more so in the developing countries. However, it again moves it away from the need for an ideological commitment to the issue under discourse. There is enough evidence to suggest that if the mechanism of intervention in the implementation process is worked out it makes more economic sense to have children in integrated set ups compared to costly special schools (World Bank 1979).

Slee (1993) reports that 'implementation of policy for facilitating integration is usually reduced to a disputation over resources'. Although this is an important point to consider, he says it looked at integration as only a technical problem.

Fears about resources can effectively paralyse progress. A wholehearted belief in the principles and rights involved would ensure that the practical difficulties imposed by resource considerations would be overcome (Barton and Smith 1987:83).

This investigation was not looking at resource availability or its distribution, but whether there was a 'whole hearted belief' in disabled children also being included as beneficiaries of provisions meant for 'all children' in the existing system. It was looking at the stages of the policy process and gaining insight about which stage of the policy-making process had not clearly spelt out the objectives and priorities of a programme meant for 'all children'. Therefore the question of resources was not investigated in depth. From the outcome of the discussions with the policy-makers, a strong statement criticising the Government's heavy reliance on the voluntary sector emerged, as it was seen as a pretext to reduce the resource allocation to this group. Since the NGOs had no political support it was mentioned that 'the NGO bandwagon was being misused by Government to save resources.' The voluntary sector taking on the Government's responsibility had made the issue into a non-issue.

Ethics of the question

This thesis did not look at the quality of the anganwadis either, because according to writers and researchers, for many reasons the local nurseries needed to improve the

delivery of service (Swaminathan 1992; Verma 1994; Siraj Blatchford 1995). Therefore qualitative aspects of the anganwadis were not being examined.

The thesis argues about the need to legitimise services for 'all' children and argued that whatever welfare benefits were being offered to other under-five socially disadvantaged children should not be denied to under-five socially disadvantaged disabled children on grounds of disability.

Integration has different significance in different countries depending on their social values, which may be concerned with equality and social solidarity (Norwich 1994:91). In the West there have been years of segregated practice with special schools available for all types of disability. In India, the disabled child has not had as many options, there being not enough special schools. Therefore the rural child or the urban slum child does not have the option to go to a special school or to an integrated school. The most cost-effective solution is to get service of some kind, and the local anganwadis run by the ICDS offers that. We are aware that all normal children do not go to the anganwadis, we are also aware that the quality of the anganwadis is not that good and need improving.

Booth (1983) argues that

Arguments in favour of integration commonly meet with the response that ordinary schools have to put their house in order calling before they should include others. In calling for an initial perfection of the ordinary school system a segregated special educational system can be retained indefinitely. But it is only by adapting to the breadth of needs within a community that schools can begin to become comprehensive (Booth and Potts 1983:27).

The thesis argues therefore about the ethical and moral position India wishes to take, in its explanation of the exclusion taking place from basic welfare services. The moral choice that has to be made is dependent basically on the kind of society we want and how education can help us achieve it. Should the children be labelled on grounds of disability and denied generally available services? Should one delay the

inclusion of disabled preschoolers until all the normal children's needs are met or enough anganwadis set up?

To comply with such a dictum is a violation of human rights.

It is this infringement of human rights that the thesis argues about. It is a question of legitimising and bringing into the safety net, the most vulnerable and downtrodden members of society, which needs addressing. The question is whether India considers that all its citizens are equal and need entitlements? The question is, whether it is a cornerstone of National Policy in India to ensure access to every citizen irrespective of race, religion, gender or disabilities to the countries basic provisions?

The study indicates that it is here, where the gap lies in the Government's functioning. Its ambivalence and silences, its inaction, its non-decision making, the values allocated to this group, indicates a lack of political and ideological commitment.

Till such time as implementation of policy takes place, the thesis argues that the ICDS policy has not addressed the question of the disabled child in its policy statement and this is why the disabled child is excluded from its practice. It argues that in the wider discourse it is the cultural milieu that was found to be disabling. The compartmentalisation, the invisible barriers, the silences, the cultural injustice and the discrimination are symptomatic of the larger fragmentation that pervades the nation, all factors which combine to prevent this issue from coming up on to the policy agenda.

Summary

The findings indicate that a lack of clarity in defining the objectives resulted in a lack of direction of policy and convergence. This did not take place in the Ministry a) at the Government level: b) at the inter-ministerial level: c) at the intra-ministerial level. Hence a lack of clear policy formulation has resulted in a lack of implementation mechanism percolating from top to bottom excluding the disabled child in the programmes not only Dharavi, but wherever the Government policy of the ICDS is being administered. The lack of a positive discriminatory statement including disabled

children has led to neglect and silence which has been maintained through the years. In policy terms, at the crucial policy formulation stage, the disability issue failed to come up on to the policy agenda. Issue identification, a crucial activity before decision-making takes place, did not happen. Goals and objectives were not appropriately spelt out. The matter was later never taken up. To this day the issue remains undefined. The lack of infrastructure to reach the length and breadth of the country, lack of adequate fund allocation has only ensured specialist centres of excellence on a micro level. The thesis argued that policy is in line with the prevailing ideology and value system and that the non-inclusion from the ICDS services reflect the wider social and institutional barriers that exist.

PART SIX

ANALYTICAL FRAMEWORK

10

A CONCLUDING DISCUSSION

10.1 The Politics of Policy-making

Historically, what becomes clear, is that although the Indian Government's statement of intent exists, about the need to integrate children with disability into the existing system of education, the policy or practice following such intent is not there. Again, although the importance of the pre-school period has been appreciated by India and the critical importance of intervention in the socially disadvantaged areas prioritised, the disabled child's pre-school needs has not been addressed. In the last fifty years since the Indian Independence in 1947, no step has been taken to create a uniform policy for disabled children, which indicates a strong absence of political will to do so.

The past affects policy-making: 'previous decisions affect policy' (Walt 1994:40). Indian policy in this situation appears to be imprisoned in its historical entrenchment--the dependence on non-Governmental organisations to provide educational facilities for disabled children. Although there would appear to be efforts made to get free from the dependence, the 'thread of conviction' (Ignatief 1992:25) is not there. Contradictions and ambiguities in administration blur the roles of different ministries, as do the Government's statements on the subject, not helping to legitimise services, as a matter of state provisions, of entitlements and rights. Policies fail if the practice does not carry out what the policy states. The policy-makers here, have distorted policy: instead of 'all' children as the constitutional directive states, they have chosen to include the normal child and remain silent about the issue of the disabled, thus failing to keep to the letter and the spirit of the Indian Constitution.

10.2 A lack of political lobby

The policy process we have seen is a political process. It is an acceptable fact that a political lobby plays a critical role in shaping and implementing policy (Kirp 1982; Barton 1984; Hill 1993; Slee 1993). Since Independence, we have seen that the disabled have been classified with other vulnerable and weaker sections of the population from socially disadvantaged areas such as women and children, the scheduled caste and scheduled tribes. These other groups have had powerful political lobby, while the disabled have been left behind and segregated.

10.3 Dichotomy between policy and practice: the structural fragmentation.

We find that although the Government continues its policy of integration on a parallel level, it has continued its segregationist policy of promoting the idea of special schools through their Assistance to voluntary organisations schemes (via the Ministry of Welfare). 'Inherited legacies' (Whitmore 1984) of conflict and tensions between the departments involved with the issue of disability abound causing a structural fragmentation.

The lack of a conceptual framework has not helped either as it has produced a dichotomy between policy and implementation, not in keeping with the declared policy of Education for All. The confusion on top has affected policy on the ground level and we find that children with disabilities are not included in Dharavi.

10.4 Voluntary not State

We find that work for the handicapped is still considered good and humanitarian acts of charity. This has not helped the issue being one of rights either. The voluntary sector has no doubt played a very active and vigorous role in introducing new concepts of education and services, but without continuous funding and good infra-structural support, it has been grounded on a micro level. In the absence of a positive contribution from the Government this group made the only critical contribution that was made. Today, because of the States lack of involvement, the vast majority, nearly

ninety-eight percent of the disabled (GOI 1994) remain outside the orbit of any service from the state.

10.5 Professionalism

There has been a school of thought that professionals may be specialised in their own area but have clung on to their specialisation and created a mystique around them for their own vested interest (Tomlinson 1982; Barton and Tomlinson 1984; Barnes 1990). Professional work has always been 'marked by conflicting interests'. Professionals have been used as experts to legitimate government action, to provide 'ideological rationalisation for state action' (Tomlinson 1983:182). Disabled children are in special schools run by people who know best and are doing good for the children with their 'deficiencies' (Abberley 1987; Oliver 1988; Mason 1992). This charity framework, with professionals dominating is similar to the situation existing in India.

10.6 Depoliticisation and Individualisation

Here in India powerful professionals, well placed and well educated, have introduced considerable technical skills into the work for people with disabilities. However, the work has been fragmented and isolated, moving away from the rights issues to an individual solution perspective. Changing Government policy, empowering disabled people and their families to lobby for their rights, the most critical thinking in the developed countries today, has not been a part of the NGO agenda, adding to the continued political weakness of disabled people. The charity mould in which they have persevered has been a diametrically oppositional position to the discourse of rights. In Dharavi, the lack of knowledge on the subject has made this group vulnerable, weak and powerless, without political lobby.

Proper representation of the disabled as a whole group in the policy making arena, has not taken place.

10.7 An ideological entrenchment

Disability cannot be treated in a vacuum. Cross-cultural literature on disability suggests that a broader view of society is needed to understand the cultural underpinnings and value systems that exist. Writers have argued that a lack of equal opportunities leading to segregation could be regarded as examples of oppression.

Policies which encourage segregated education for some children on the grounds of any disabilities or difficulties they may have or are presumed to have, is an example of oppression (Barton and Smith 1987:77).

The thesis argues that this kind of oppression where there is a division being created, on the grounds of disability, is happening in Dharavi. Disabled children have a lower value and therefore they are denied their rights: the rights of the 'normal' as socially determined are supposedly greater.

Crucial to the findings of this study, is an ideological and cultural mind set against disabled people emerging, as a major obstruction in accepting them. Quite often articulated by disabled people themselves, the thinking that societal attitudes are a greater disability than a disability itself has been expressed by many writers.

Handicap is determined by society through its laws, norms and institutions and not by disability. The degree to which situations are handicapping depends very much on the community, its attitudes and its provisions for individuals who form part of it (Fish 1985:5).

Questions of morality and ethics raised by philosophers over centuries are: who oppresses whom? In the ultimate analysis, what is the norm? Who is normal? Foucault (1967) questioned concepts of madness and reasonableness and wrote how it was society that decided these concepts. He started from the hypothesis that madness had something to do with excluding some people from society, especially, by confining them and locking them up. He challenged assumptions and definition of abnormal and normal and argued that societies and the human sciences since the

eighteenth century carefully defined the difference between the normal and the abnormal and then used this definition to regulate behaviour. Distinguishing between the two he argued may appear to be easy but is in fact very difficult as there is a hazy and highly contested borderline. Society historically locked up, excluded and hid what they considered abnormal people (Foucault 1961).

In the Indian context, the prevailing deep-rooted prejudice has created the split between normal and disabled. Underpinning the marginalisation of disabled children that has taken place in India, are stereotypical cultural and social values dominating the minds of people. This has affected the status in which disabled children are regarded and the way they are separated from the rest of their peer group at an early age.

A cultural injustice, resulting in social and educational exclusion of one of the vulnerable and weakest groups of society, has become historically entrenched.

The discourse of invisibility: the reason d'être for disempowerment

In the wider context, the child being still hidden away, not included in the Census of India, is a key issue. The finding that not any of the Government's teacher education syllabi include pedagogic issues concerned with the teaching of disabled children is another key issue. Power and Knowledge, Foucault argues, are like 'two sides of a single process inseparable and inter connected' (Ball 1990) without either of these conceptual supports, the disability group remains invisible and powerless.

The investigation provides substantive evidence indicating the following:

The Indian nation has not recognised the fundamental rights of the disabled group, nor made any critical attempt to remedy the lacuna that exists in their policies since Independence. The policy and practice of doling out grants to organisations during the post-Independent period seem to be similar to what was happening in pre-Independent India a hundred years ago.

Present Government policy towards disabled children is equivocal and full of ambiguities, principally dependent on voluntary organisations to deliver services.

Government's assistance in the way of grants-in-aid to voluntary organisations has become officially accepted State policy.

Government's continued reliance on the NGO sector absolves it of its responsibilities towards the disabled as citizens with their own right. Government's conflicting ideologies within the structural framework of the Ministries of Education and Welfare continue to cause conflict and tensions indicative of a lack of convergence.

India is amongst the few developing countries where the State relies heavily on the voluntary sector for providing basic services for the disabled. This reliance has contributed to a micro level spread and a two percent coverage. The services remain patchy and far from uniform around the country, covering only the tip of the iceberg. Rural areas still remain out of reach and considering the fact that the majority of disabled people live in these areas, this very significant group of the Indian population remains neglected.

The Ministry of Welfare's failure to network effectively with other Ministries, to ensure that each Ministry includes rather than excludes disability, has resulted in the disabled being cut off from other Ministries and excluded from services. The fact that the Ministry of Welfare does not have educational services as part of their agenda, has also increased the marginalisation; a lack of demand for more resource allocations has resulted in economic and political marginalisation of the Ministry of Welfare itself.

The Non Government sector has pioneered valuable services, ensuring social integration into the community; however, with limited infra-structural services, and funds the voluntary sector has only served on a micro level. Again, although the NGOs may have contributed excellent services they have been involved in a service delivery approach and not in the area of advocacy and rights approach, thus contributing to depoliticisation. The hegemony of the professionals could be seen even in a semi-literate slum like Dharavi, where the community believes that special schools are the right place for children with disability.

'Education For All' could remain an empty promise on the part of the Government of India, if there are no plans for operationalisation of policy into

practice for the inclusion of children with disabilities. Today, due to the State's non-involvement a staggering number of ninety eight percent of India's disabled people does not receive any care from the Government (GOI 1994). Due to the unaccountability (a result of political weakness of the group) this is not been questioned.

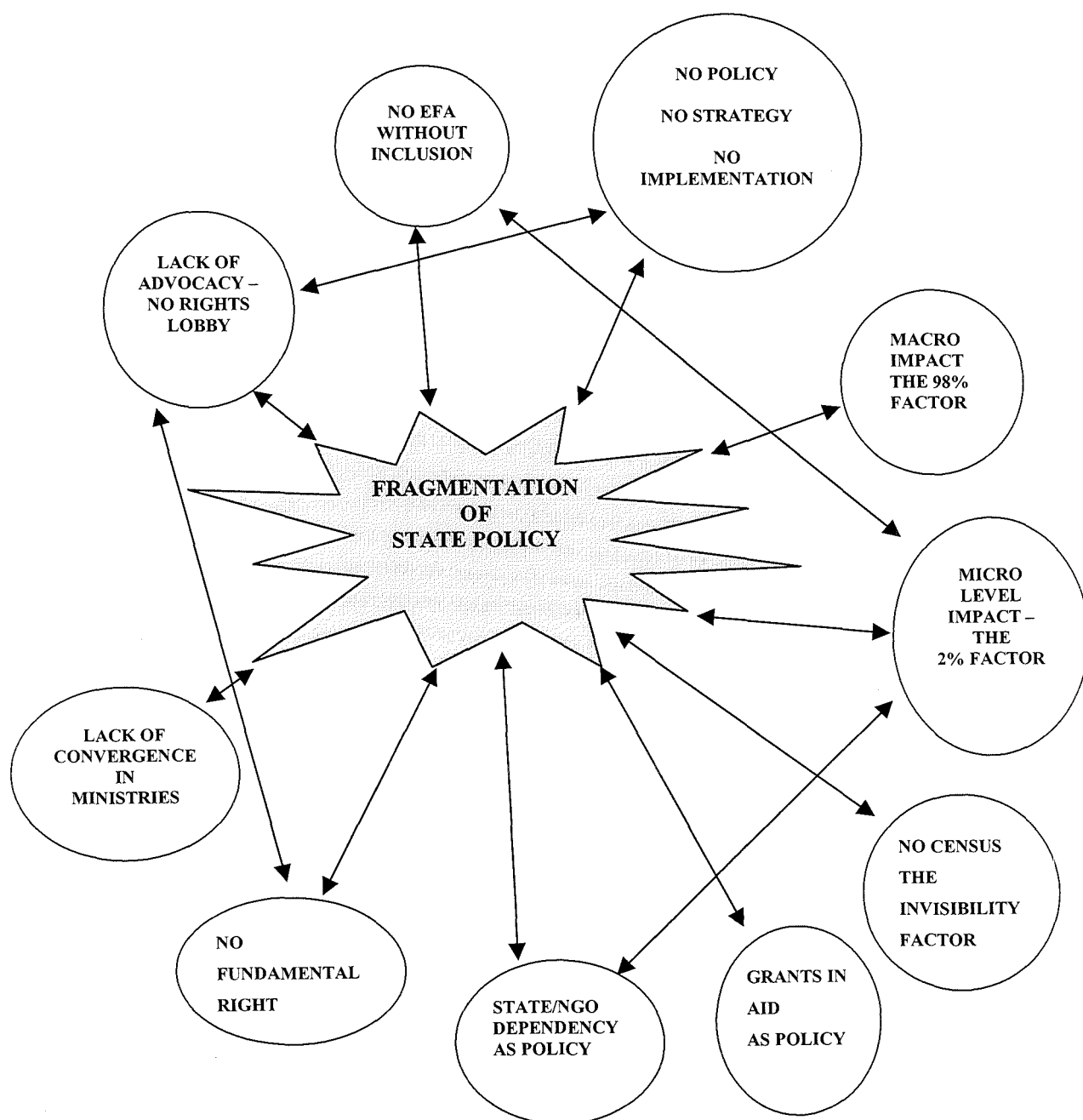
Leaving out disability from the Census of India has relegated them to the wilderness in which they now belong, not to be seen or heard.

Invisible groups do not need policy or financial allocations.

Lack of a policy directive and financial allocation has ensured marginalisation, which is why the disabled child is barred from Government's local nurseries in Dharavi. The ICDS policy of non-inclusion of disabled children into their programmes is symptomatic of the wider malaise in Indian Society, indicating an overall policy of exclusion.

Figure 10 overleaf illustrates the factors from the investigation that could have contributed to the fragmentation of policy.

Figure 10: A policy formulation and implementation framework: distortion of policy resulting in the non-inclusion of disabled children due to wider ideological, political, structural fragmentation



In conclusion

It has been said that 'among the most deep seated fears is that of the unfamiliar' (Corbett 1996:4). The unfamiliar cannot become familiar or a part of us unless it is properly defined and conceptualised. Therefore, precision in the use of language connected to disability is crucial for conceptualisation of needs to take place. To a certain degree the required change in nomenclature in the West has already taken place. Emphasis now is on teaching and learning, on interacting with the environment (Wedell 1982; Hegarty 1982), on understanding the needs of a wide range of diversity (Tomlinson 1982; Booth and Potts 1983) on moving away from labelling (Tomlinson 1982; Barton 1984; Fulcher 1989). In the Indian situation to fill the gap between the familiar and that which is unfamiliar still remains a key issue. For this a redefinition of terminology and targets is needed.

Therefore, the issue first needs to be defined. Issue definition will help to prioritise and differentiate the needs of disabled children and begin to set out clear objectives for the implementation mechanism to be designed. For example in order to bring disabled children into the safety net a redefinition of the term 'all' in 'all needy children' to include 'disabled children' as well needs to be urgently addressed. It has to be clearly appreciated that policy, defining the issue that as far as 'all' is concerned is meant to include and not exclude disabled children needs to be stated, suggesting explicitly, specific objectives to be put into practice. Clearly, non-decision-making (Bachrach and Baratz 1977) has been a key factor in keeping the children out of the network of services. Policy has been too long silent and ambivalent, with a tacit understanding amongst the policy-makers, that disabled children are not to be brought into the services of the ICDS policy due to the difficulties this inclusion may cause.

Policy cannot be put into operation if the issue is not a part of a policy agenda and has not been addressed. The mechanism then, which at present does not exist, can be addressed. Codes of practice, putting policy into action can only be done if a decision to include this group of children is taken and the resource allocation is

made. Silence and ambivalence on an issue only indicates Government's lack of intention to take up the issue and to put policy into practice.

The present situation indicates that urgent steps need to be also taken to empower the disabled group. The equal opportunity debate has to be carried forward. The empowerment/entitlement discourse is therefore critical to address. Policy is affected, if the voice of powerless groups cannot be heard (Bachrach and Baratz 1984; Lukes 1974). The issue being thought of as a 'personal tragedy' or an 'individual problem' has no role to play in moving the discourse to one of human rights.

The disabled tend to be losers in a situation which is divided up by those who are able or whole, and those who are unable and less than 'whole' (Christensen 1996). This labelling is disabling. It gets attached to a human being for her entire life and the person is viewed as 'cerebral palsy' (in India still labelled as spastic) or blind, or 'm. r.' (intellectually impaired) epileptic. Even worse labelling takes place in society where people are called 'moron' (Corbett 1996) 'cretin', 'cripple'. Labelling human beings dehumanises them. Their self-worth gets devalued. It reduces them to objects of pity, sympathy or in need of patronage, which society is ever ready to dole out, because it makes them feel good in doing so.

Although, the thesis is a study of a particular country, India, it has underpinnings that are universal. Disabled people all over the world are the poorest segments of the population, and suffer varying degrees of oppression. Societies in the developed countries, although more advanced in the services they offer, still continue to classify them as being 'special' 'different' needing a separate set of rules to govern their lives. They need special homes, special units in schools, special areas for them in the theatre in the cinema, thus in a subtle way putting them apart, distancing them because of their differences. The labelling that takes place in the Western society is explained, to be necessary, in terms of resource allocation and organisational changes. Although, the resource element in the argument of labelling has been an important question to answer, there has to be a way out. Resource allocation cannot be a criterion for classification of human beings as 'special' not normal, needing different arrangements. Granted, that a certain amount of adaptations will be always necessary, in dealing with the different kinds of disability, however the principal aim

should be one of inclusion enabling them to be integral parts of a homogenous whole while remaining different in particular aspects. 'The problem is not how to wipe out all differences but how to unite with all differences intact' as said Rabindranath Tagore.

The thesis has argued how societal attitudes disable people. A person can overcome a disability, but cannot overcome the entrenched negative beliefs. Social exclusion takes place when human beings are stigmatised and put into narrow pathologised boundaries. The practice of non-inclusion has its niche in a complex social system. The social system within a highly stratified hierarchical set up such as Indian society submerged in concerns of class, caste, gender, religion, is highly detrimental to social change. To change it to a society where people value each other despite differences moves the discourse into the philosophy of egalitarianism and equality of opportunity for all, which is a utopian situation difficult to achieve. However, a civil society built on the dogmas of social justice and equal opportunity recognises the weak, the needy, and the helpless. This conforms to the spirit of the Constitution and yet it is overlooked in the context of the disabled child.

According to Voltaire the 'civilization of a nation depends on how it best takes care of its most needy and helpless'. Non recognition and Invisibility; disrespect and 'being routinely maligned or disparaged in stereotypical cultural representations' (Fraser 1995:71) with all its antiquated beliefs and superstition, renders the issue to be one of a discourse of cultural oppression and social injustice. A discourse of what constitutes normality needs to take place. Unless this issue is properly addressed it results in 'devaluation, derision and degradation' of a human being (Ibid: 72).

Educational practices are embedded in a larger framework of value system. The values of egalitarianism, social justice and moral ethics are values that need to have proper recognition in a society. It would need major economic and social transformation to take place to change attitudes to develop equality in education. A reallocation of these values is needed urgently. Educational egalitarianism can lead to empowerment. This is specially so when majority of families investigated by the study are caught in the grip of poverty and deprivation; their powerlessness leading to an unquestioning compliance with societal norms.

It was C. Wright-Mills who first made a distinction between 'public issues and private troubles'. He wrote that 'men do not usually define the troubles they endure in terms of historical change and institutional contradiction' (Wright-Mills 1959:14-15) and that troubles tend to be defined by individuals as their own problem and often their own 'fault'. However he believed, that 'issues are social property - they transcend the environment of the individual'. Disability is not an individual and private tragedy. It is a social problem, a nation's responsibility. Although essentially a policy study, an important issue running through, was a philosophical one, concerned with the ethics of a civil society, whether or not it should be separating their children and denying facilities on the grounds of disability.

Progress will depend on the moral base and ethics of the decision, a decision to address, or not to address the issue. Will India continue to only address the socially disadvantaged scheduled caste child, and the girl child, and continue to leave the third group of the weaker section out, so creating an underclass within an underclass, or should India address the issue of 'all children' to include disabled children as well?

Ingrained attitudes do not change quickly. No single strategy will provide the solution. Undoubtedly, it will be a Himalayan task, but clearly the lives of all children being precious, with some children doubly impoverished, this becomes a critical issue to resolve. The present social structure reinforces institutionalised discrimination: thus the target to reconstruct and to redefine becomes critical.

The voluntary sector who have played a major role historically, will need to spearhead the action, first, by moving towards a change of the ideological bias and the faulty misconceptions about disability that exist: and second, by a desegregation of their own institutions moving towards a social model of inclusion. Radical improvement will not take place overnight. One is talking of incremental movement.

The first incremental step could begin with describing 'all' in the policy documents if the meta goal of achieving Education For All is to be reached. As mentioned earlier, a discourse of what constitutes normality, needs to be redefined to place disabled children within a national framework of provisions. Among the

different forms of intervention for future action, a demystification of language, faulty beliefs, connected with the issue is needed for acceptance on the ground level. A deconstruction of the existing ideological framework which is suffused in mythology, superstition, stigma (a problem that applies particularly to India) needs to take place creating a situation where the positive aspects of the problem can come up: with a target to pull down and demolish the 'Berlin Wall of Segregation' that has for long obstructed the policy-makers in India.

PART 7

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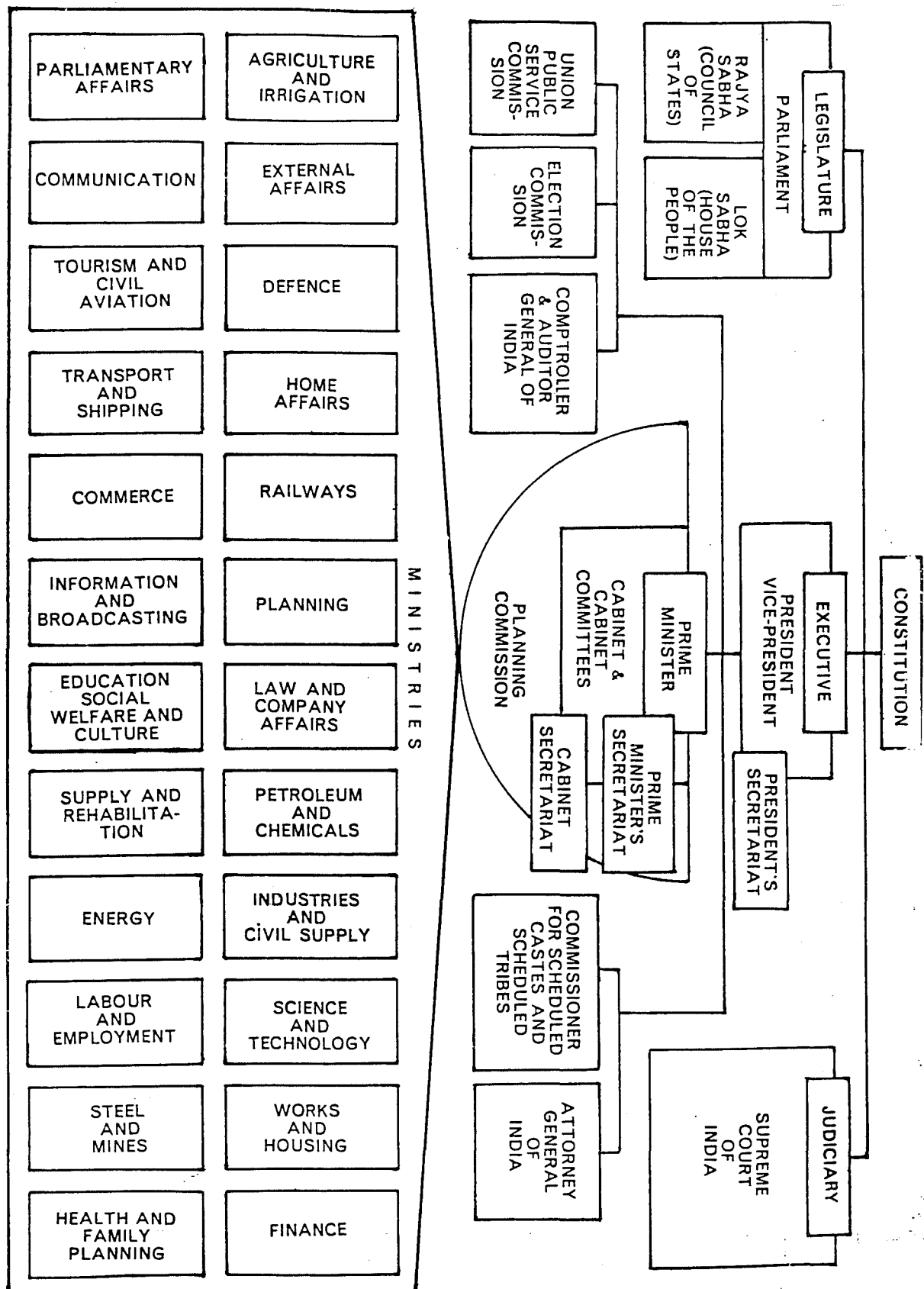
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Appendix 1: Structure of the Government of India*



* The names and structure of Ministries change from time to time. The Ministry of Welfare is now known as the Ministry of Social Justice and Empowerment and is separate from the Ministry of Human Resources Development which includes the Ministry of Education.

PICTURE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES



Rabindranath Tagore,
New Birth, 1940

The Young Child's Right To Survival And Development — Our Responsibility

“State to provide adequate services to children, both before and after birth and through the period of growth — to ensure their full physical, mental and social development.”

(National Policy for Children, 1974)

“State parties recognise that every child has the inherent right to life. State parties shall ensure, to the maximum extent possible, the survival and development of the child.”

*(Excerpts from Article 6 of the UN Convention on the Rights of the Child.
Ratified by the Government of India in November 1992)*

ICDS seeks to translate the national commitment to promoting the young child's right to survival and development into a reality — in nearly 70 per cent of India's community development blocks and 260 urban low income group pockets.

PICTURE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES

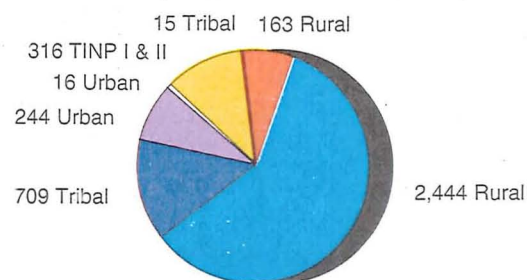


Coverage and Outreach

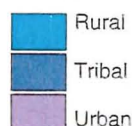
The ICDS programme was launched on October 2, 1975, the 106th birth anniversary of Mahatma Gandhi, the Father of the nation. This signifies commitment to the Gandhian vision of addressing socio-economic inequities — by reaching out to the most disadvantaged, underserved — and the most vulnerable. As Gandhiji saw India's development in the empowerment of its people, so does ICDS seek to empower communities for the care and development of their children and women, to shape the country's present and future.

Started on an experimental basis in 33 blocks, the programmes, by March 1995, covered 3,663 of a total of 5,239 community development blocks in the country through 3,907 projects. This includes 260 projects covering urban poor pockets. Over 6 lakh persons are involved in promoting basic healthcare and pre-school education activities under the scheme.

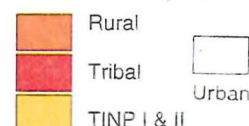
Central And State Sector Projects Distribution
(3,907 Projects, As On March 31, 1995)



Central Sector Projects

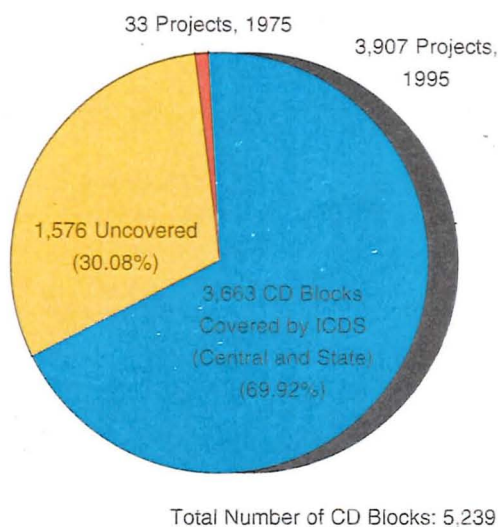


State Sector Projects



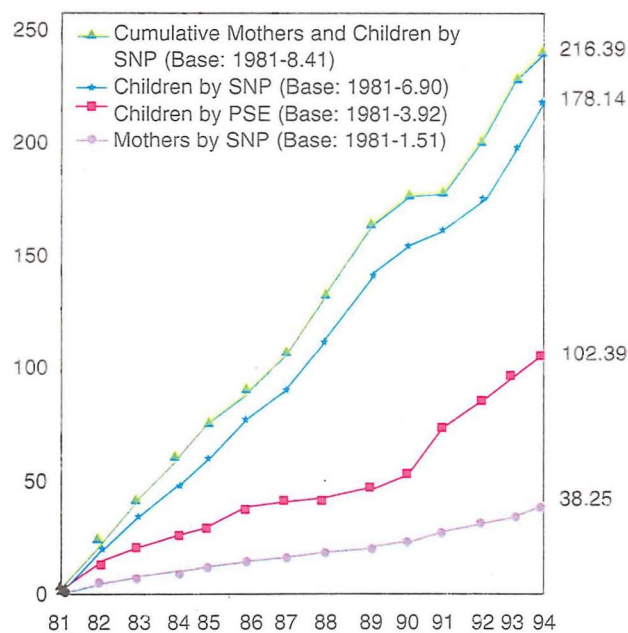
The above is the distribution of the Total Number of ICDS Central and State Sector Projects (not CD Blocks).
Source: Department of Women and Child Development, Ministry of Human Resource Development, Government of India.

Expanded Coverage Of CD Blocks
(As On March 31, 1995)



Note: Difference of 224 in the number of ICDS Projects (3,907) and CD Blocks (3,663) is due to Urban projects, Twin blocks and reorganisation of some blocks.

Coverage Of Beneficiaries
(In Lakhs, As On March 31, 1995)



- * Nearly 300,000 AWCs
- * Cadre of Trained Functionaries
2,764 CDPOs/ACDPOs
12,479 Lady Supervisors

- * Network of Trained Community-based Female Frontline workers at Village level
- * 2,92,951 Anganwadi Workers (AWWs)
- * An equal number of Anganwadi Helpers (AWHs)

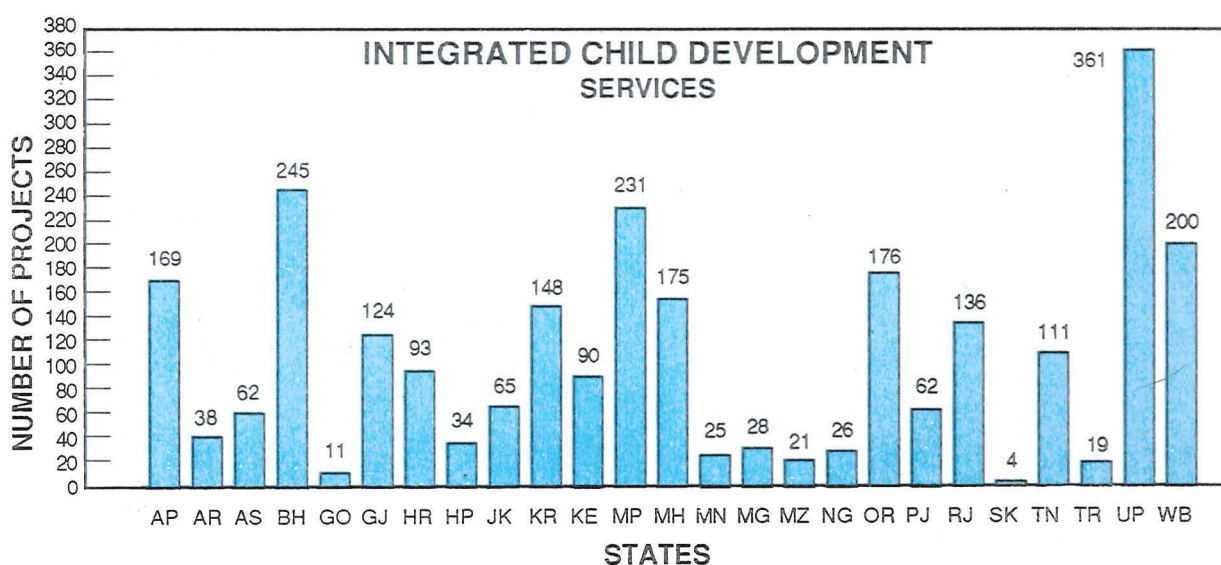
Source: Department of Women and Child Development, Ministry of Human Resource Development, Government of India.

PICTURE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES



ICDS Objectives

- * Improve the nutritional and health status of children in the age group 0-6 years.
- * Lay the foundation for proper psychological, physical and social development of the child.
- * Reduce the incidence of mortality, morbidity, malnutrition and school dropouts.
- * Achieve effective coordination of policy and implementation among various departments to promote child development.
- * Enhance the capability of the mother to look after the normal health and nutritional needs of the child, through proper health and nutrition education.

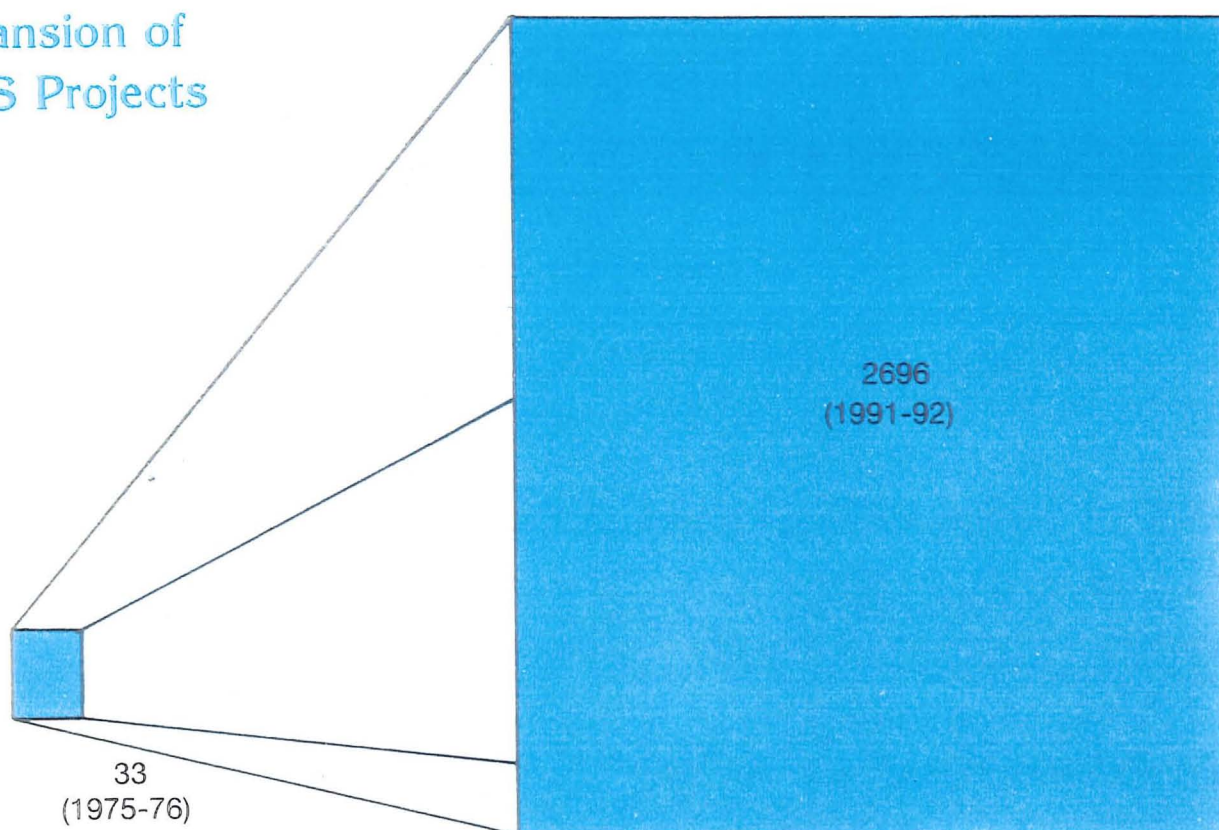


ICDS: Growth and Development

The ICDS programme was launched on October 2, 1975, the 106th birth anniversary of Mahatma Gandhi, the Father of the Nation. Started on an experimental basis in 33 blocks, the programmes, by March 1992 covered 2461 of a total of 5153

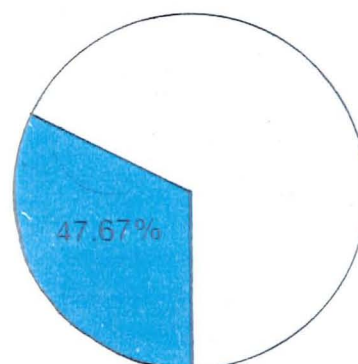
tribal/community development blocks in the country. In addition, there are 235 ICDS projects in urban areas. Over 5 lakhs persons are involved in promoting basic health care and pre-school education activities under the scheme.

Expansion of ICDS Projects



Community Development Blocks under ICDS

Total CD Blocks in the Country as on 1-1-1990	5153
Coverage by ICDS so far:	2461
Urban ICDS projects	235

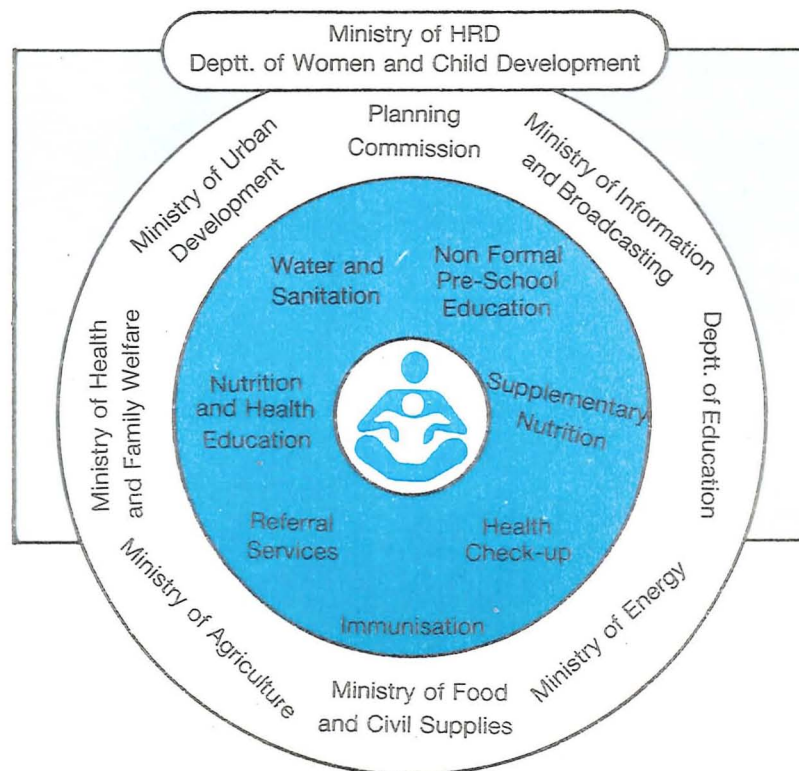


Learning from Experience

ICDS experience since 1975 has taught several valuable lessons with a larger applicability to programmes for the development of human resources:

- * Community level, honorary, female workers can be effective and viable instruments of human resource development if these workers are supported with training guidance and necessary material inputs.
- * Collaboration of academic institutions is very useful in providing, at low cost objective feedback on the programme and continuing education to workers. The educational process in the academic institutions is also enriched with the field experience of the programme.

Integrated Services



- * An integrated approach, including a package of mutually supportive services, is more cost effective than individual services delivered separately.
- * The ICDS type of network makes it feasible and easier to apply new, simple technology on a larger scale.
- * Flow of human and material inputs has
- * Large scale expansion of human resources development activities requires considerable delegation of administrative and financing decision making to lower levels of administration. Delegation has to be real authority commensurate with responsibility—so that it improves administrative capacity for implementation.

Looking Ahead: The Vision

The National Policy on Education, 1986, National Programme of Action, 1992, and the National Plan of Action for Children, 1992, have reinforced the priority to promoting early childhood care and education, through approaches for holistic child development. Emphasis has been laid on the use of child-centred playway activities, to nurture joy, curiosity and creativity in the young child. The early years are the crucial foundation for cumulative life-long learning — a time of opportunity, in which even small positive changes can generate long term social benefits. An opportunity that can make all the difference to the child from disadvantaged groups, the girl child and also to the child with disability. An opportunity that also results in increased cognitive and social skills, improved enrolment, retention and learning in critical early primary grades. An opportunity that determines both the present and the future.

ICDS embodies a unique integrated cost-effective approach for holistic development, converging basic sectoral services, where child survival, growth and development go hand in hand. ICDS also seeks to strengthen the capacity of caregivers and communities for childcare and early stimulation, by building upon local knowledge and child care practices — to provide a nurturing physical and social environment for the young child in the family, community and at the AW centre.

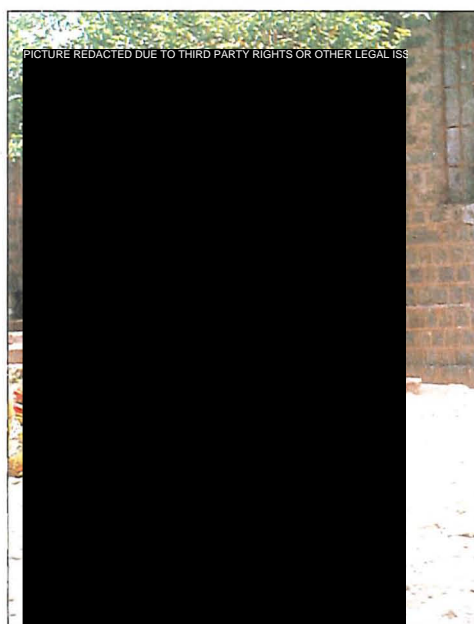
The experience developed over the years has helped to strengthen early childhood care and education processes and to forge stronger linkages with the education system. Emphasis is being laid on addressing both socio-economic and gender inequities by promoting development and learning opportunities for the young child, the older girl released from the burden of sibling care, the adolescent girls and women's groups reached by the ICDS network.

Emerging from two decades of rich experi-

★ "Learning begins at birth ..."
(Article 5)

(Jomtien World Declaration on
Education For All, 1990)

ence, today the task ahead is not only that of tackling disease and malnutrition — but of promoting every child's right to development.



ICDS has also now reached a stage where it is essential to harmonise the expansion of the programme and its content enrichment. The spectrum of ICDS services has broadened with interventions related to the empowerment of women and communities and convergence of sectoral services. This emerging profile of ICDS rededicates itself to promoting early child development — the foundation of human resource development — the vision.

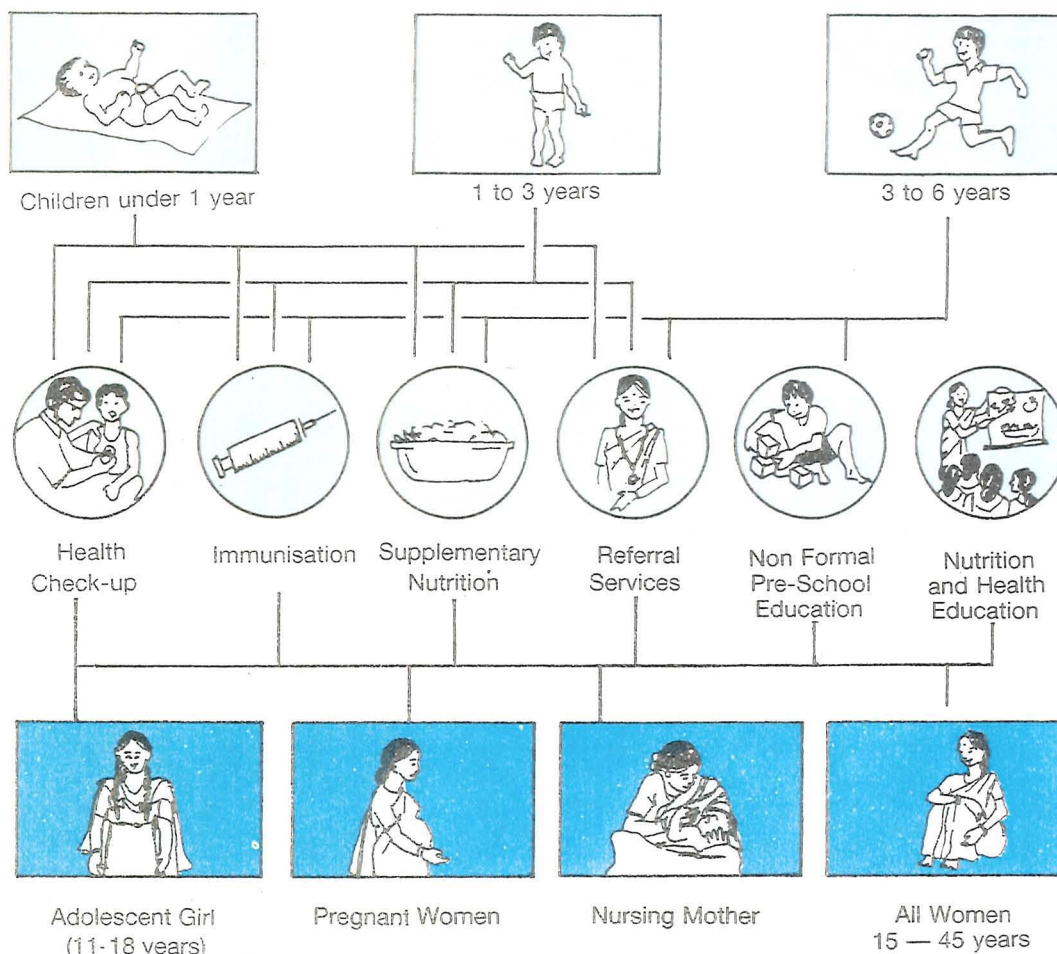
The opportunity is the universalisation of ICDS. Priority needs to be accorded to malnutrition prevention, as this is a major risk to child development.

The challenge is achieving National Plan of Action goals for reducing severe and moderate malnutrition by half, among children under five years of age, by 2000 AD from 1990 levels.

The vision for tomorrow, is founded on the opportunity. To reach every child from disadvantaged groups. To enable every child to realise full development potential, with learning opportunities in early childhood — especially the girl child.

The partnership at community level — between frontline workers of different sectors and community/ women's groups can make our vision a reality.

ICDS: Services and Beneficiaries



Through the Anganwadi, the ICDS services converge at the same time on the same adolescent girl group of children, as well as on pregnant women and nursing mothers. This pattern is based on the concept that services for children must operate together for any of them to have a durable value and lasting impact.

For instance, supplementary feeding for mainnourished children becomes more effective if accompanied by health check-ups, immunisation, diarrhoea management programmes, clean water, mental stimulation and basic health education for mothers.

The ICDS package provides: Health Check-ups, Treatment of minor ailments, Referral services.

Supplementary nutrition; Pre-school education (to children in the age group of 3–6 years), Nutrition and health education and Convergence of other supportive services like water supply, sanitation etc.

Health

At the Anganwadi, children adolescent girl and pregnant women and nursing mothers are examined at regular intervals by the Lady Health Visitor (LHV) and Auxilliary Nurse Midwife (ANM) who also administer diagnose minor ailments and distribute simple medicines. They provide a link between the village and the Primary Health Care sub-centre

New Initiatives

✧ ICDS Training

- Introduction of sandwich training curriculum for training of Anganwadi workers.

- Alternative field-based refresher training approaches being tried out.

✧ Preventing malnutrition (in children under two years of age)

- Through strengthened integration with health and usage of immunisation contact points.

- Focus on 'promoting complementary feeding and Oral Rehydration Therapy (ORT)', during the 20th year of ICDS.

- Age and gender specific analysis of MPR for improved action.

- Community-based monitoring of nutrition status, using community charts.

- Making supervisors directly responsible for monitoring and follow-up of malnourished children.

- Upward revision of cost norms for supplementary feeding.

✧ Early Childhood Care and Education

- Strengthening project level resource centres at CDPO's Office.

- Coordination of AWC timings/location with primary schools.

- District training teams approach.

- ✧ Strengthening of the ICDS Management

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Information System.

- ✧ Community-based monitoring and mechanism — Baal Vikas Mahila Samitis with participation of panchayati raj institutions.

- ✧ Convergence of intersectoral services and Indira Mahila Yojna.

- ✧ State-specific initiatives, demonstration models and exploratory try-outs encouraged.

- ✧ Involvement of voluntary organisations/NGOs in ICDS.

- ✧ Focus on backward and most disadvantaged areas — 180 focal districts with adverse female-male ratio and child labour concentration.

- ✧ Plan for Introduction of Services (PIS) in new blocks.

- ✧ Strengthening of basic infrastructural facilities under social safety net (including storage facilities for supplementary food).

Preventing Malnutrition In The Young Child (Under Two Years Of Age), With Emphasis On The Crucial First Year Of Life

- Universal early registration of pregnancy — enabling utilisation of key services, that is, Antenatal Care (ANC), immunisation against Tetanus supplementation, and improved care and counselling of pregnant women, to ensure appropriate and adequate food and rest. This is also likely to reduce the incidence of low birth weight.
- Promoting the practice of exclusive breastfeeding of children from birth to four to six months of age, timely immunisation and counselling for appropriate care of low birth-weight babies.
- Promoting appropriate and timely complementary feeding, with the use of local household resources, starting among infants at four to six months of age (with continued breastfeeding up to two years).

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- Improving coverage of nine-month-old children, with measles immunisation and vitamin A supplementation, and checking that each nine-month-old child receives at least four complementary feeds per day.
- Improving the management of diarrhoeal diseases (with ORT and continued feeding) and acute respiratory infections at home, through Anganwadi centres and through health facilities.
- Strengthening growth monitoring and promotion of young children (especially under two years of age), with the participation of mothers/communities.
- Promoting consumption of only iodised salt.

Appendix 3: Questions used in the Community: Focus Group discussions, semi-structured interviews, triangulations with Groups A, B, C and D

Focus Group A: Parents of Disabled Children:

1. What kind of services are disabled children getting in your neighbourhood in the areas of i) health; ii) nutrition; iii) pre-school?
2. Do any of your children go to the anganwadis? Why not? Do you think they should go to the anganwadis? What would be the difficulties for parents to get them into anganwadis?
3. What kind of services do you think would be beneficial to you and your child?
4. What are the advantages of disabled children studying in the local anganwadis?
5. “Let us talk generally, not specifically about your child but of all disabled children around you in the community”.

Do you know of other parents with disabled children like yourselves? What are some of their experiences? How do their families generally react to the child and how do their husbands and in-laws react? What kind of difficulties do parents face? Why do you think these difficulties exist?

Focus Group B: Parents of Neighbours

6. Do you think the disabled should be included into the existing anganwadi and balwadi services?
7. What do you feel about disabled children? Do you think its anyone's fault?

Focus Group C (i): Anganwadi workers

8. Why do you not have any children who are disabled? Why do you think mothers of disabled children do not come for this service when it is just next to them?
9. What do you think would be the practical problems if disabled children were included?

Focus Group C (ii): Supervisors

10. Why do you not have any children who are disabled? Why do you think mothers of disabled children do not come for this service when it is just next to them?
11. What do you think would be the practical problems disabled children were included?

Appendix 4: Interview Schedule for Ministry Officials at the Central level in the Education Departments dealing with Disability Early ICDS Child Care and ICDS programme.

ICDS Policy and Practice for NIPCCD which is the training agency for the ICDS

1. Is the service also used by under 5s who are disabled? Is there a policy to include disabled children in these services?
2. What kind of changes will be necessary in the teacher training if inclusive education was to be practised? How do you envisage these changes taking place?
3. Why do you think disabled children have not been included? Why do you think mothers of disabled children do not go for this service when it is just next door to them?
4. Is research being conducted at present for the Under 5s? If so do the findings show any State programme where disabled children are being included in the ICDS pre-school settings? (Only for NCERT, CTC, main research units of ICDS).

Wider issues:

5. What do you think is the rationale for not including the disabled child in the ICDS programme? Have provisions for disabled children been made? If so what kind of provisions have been made?
6. What is your opinion? Why do you think over the years, since Independence there has not been a mention about the disabled child in this policy?

7. Considering the Government has taken a major decision in their DPEP programme to include disabled children, what kind of practical modification and financial allocations have been made for the child to be integrated into the ICDS programme?

Appendix 5: Questions used for the Policy-makers

1. What was the explanation for the ICDS not explicitly excluding, but not directly addressing, the needs of the pre-school disabled child within their existing provisions for the weaker and vulnerable sections of society?

(a) When was the policy made and by whom? What were the priorities? How did the issues come up on the policy agenda? How were they defined? What and how were the objectives and goals of the programme decided?

The questions were designed around the wider theoretical and conceptual framework mainly the philosophical and ideological issues, the socio cultural value system, the historical and political processes, the structural and organisational elements, the economic issues, the educational issues, the policy and implementation issues, narrowing down to the question of the issues that needed to be addressed to fill the gap that existed.

The Key Research Question:

The questions were planned to generate the information required to answer the research question. Questions designed around these issues are given below

The wider issues which were covered around the Research Question:

Education Policy and implementation:

Qs. What kind of policy, goals and plan exists for educating disabled children?

What are the main stumbling blocks to the implementation of the Sargent recommendations? What are the problems you envisage? What kind of intervention do you think remains to be done which will be helpful for the implementation process?

The Sargent report had recommended that education of the disabled child should be a part of the normal educational system. Which are the departments within the Ministry of HRD responsible for the education?

Historical and philosophical:

Historically speaking, there is a Statement of Intent, which appears to include the disabled child, so what could have happened do you think to keep the child out of general provisions?

Ideological and cultural context:

Could some of the wider socio-cultural beliefs and mores that influence us within our very stratified society stratified under caste, religion, gender influence this issue?

Have beliefs in karma ... our thoughts about the past influenced our thinking? Is there some deep-rooted feeling about this? Could this have some influence on policymakers on the decision-making levels?

Sociological ... the sociological context in which policy can get embedded:

I am interested in the wider socio-cultural, political and ideological framework within which the ICDS practice exists?

What kind of a society do we have? What kinds of attitudes prevail? What kind of explanations do people give about disability? Can we say this is only in the semiliterate and rural areas? Would it affect educated people like the policymakers or us...?

Why do you think the scheduled caste and the scheduled tribes get certain provisions and the disabled do not?

Political: How do you think the NGOs have helped?

Appendix 6: Specific Techniques used for Focus Groups

Focus groups some field notes

I asked the group to begin introducing themselves and tell us about her disabled child and her other children. Although quiet at the beginning they all opened up within half an hour. The moderator involvement tended to be of a high level, although non-directive, to ensure that there was free group participation and not one or two people dominating (Krueger 1994), as tends to happen in the slums with the more aggressive and articulate type of person. I was able to play several roles as are possible in focus group discussions: moderating, listening, and observing. Half way through the discussions, the tea and snacks helped and was a good strategy in getting them relaxed and enjoying the interaction. When talking about the attitudes of the community and the family, mothers were reticent, which was expected. But being in a group situation that had a kind of neutrality they tended to talk quite freely. They also seemed to be encouraged hearing others talk.

Treating them as people contributing to the work.

- These were busy people and it was important to mention that one was aware of this and to treat them in an equal rather than a patronising manner. Having a long introduction where they had a chance to talk about their disabled child gave them a chance to unwind. The physical proximity of sitting on the floor with them, having a cup of tea etc helped in building the rapport.

Context specific: knowing the language they spoke.

- Knowledge of the language was important as frequent translations do not keep the researcher in control and can interrupt at critical moments.

Reframing questions

- Questions had to be framed indirectly, when talking about sensitive subjects such as the attitudes of those pertaining to the family and the community.

Mothers had to be spoken on a one to one basis

- Mothers were reticent. This was very typical of the Indian scene where people tend to be scared to open up, especially so in the slums where there is a greater mistrust and suspicion of authority: women being hesitant and scared to open up in front of others but doing so during the triangulation's.

Separation of the parents due to a gender domination of the male

- The separation of mothers and fathers was also a culture specific move, which gave insight about what they felt about the birth of their child and about the role of their wife and mother in law as reported in the chapter on Findings.

Home Visits.

Informal visits at home and discussions in a relaxed atmosphere were also critical for exploring sensitive issues.

Appendix 7: Observation of anganwadi schedule

1. Name of the School:
2. Location:
3. ICDS Code Number:
4. Number of children:
5. Disabled Children, if any:
6. Types of Disability:
7. Surroundings:
 - a) Type of approach, paved/unpaved
 - b) Typical occupation in the neighbourhood
 - c) Type of households – authorised/unauthorised
 - d) Other on-the-spot observations
 - e) Availability of water
 - f) Type of toilets
 - g) Type of houses
 - h) Any other.
8. About the Classroom:
 - a) General Observation on size: small, medium, large:
 - b) Description of the room
 - i) Furniture
 - ii) light

- iii) air
 - iv) other
 - c) Is the room adequate for meeting all children:
 - d) Was the classroom door open or shut? Why shut
 - e) Teaching material, if any
 - f) Toilet facility
 - g) Drinking water
 - h) Where is the nutrition supplement cooked?
9. About the teacher:
- a) Age:
 - b) Basic qualifications:
 - c) Experience
 - d) Language of communication:
 - e) Type of training
 - f) Guidelines on curriculum, if any:
 - g) Duration of Training:
 - h) Refresher courses attended:
 - i) Is the classroom in her house:
 - j) If not, the distance from school, and,
 - k) Other information about her family:
 - l) Where does she refer disabled children:
 - m) Can disabled children come to her class:
 - i) Why not?
 - n) Would she like to work with special children?
- i) Why or why not?

Appendix 8: NGOs in Dharavi

The Spastics Society's Service Karuna Sadan and CORP

The Spastics Society of India (SSI), Karuna Sadan at Dharavi provides the following services:

- Early identification of disability
- Assessment
- Pre-school education

- Therapy and treatment
- Early stimulation
- Provision of aids and appliances
- Training courses
- Home management and parent training
- Family counselling.

Together with the local authority hospital personnel, SSI also provides:

- Training of community health workers and anganwadi workers.
- Community awareness programmes
- Regular courses for MBBS students
- Certificate courses for anganwadi workers

Community Outreach and Rehabilitation Programme (CORP)

CORP has one Balwadi especially for disabled children. At present, they have 27 children with hearing impairment and four with speech and communication handicap.

Other activities of the centre include:

- Creche
- Supplementary study programme for disabled in this scheme, children with disabilities who cannot cope with curriculum in regular schools are given free one-to-one tuition by teachers trained at CORP
- Non-formal education for school drop-out
- Nutrition programme and mid-day meals
- Provision and maintenance of hearing aids
- Need based speech therapy

Teachers and social worker of CORP carry out community visits to identify deaf children. The method they use for identification, assessment and evaluation is not known. The children are brought to the Balwadi for four hours every day. The model of education and nutrition supplements is similar to ICDS. There are two helpers who go from house to house to bring the children in. Unlike ICDS, they are given a full meal in the afternoon. Children are given free books, slates and clothes. Need based Speech Therapy is provided. For audiometry and hearing aids, children are sent to NIH. Free hearing aid batteries are supplied. Children attend the service till six years of age.

The community workers at CORP maintain close contact with Karuna Sadan. Often children with multiple disabilities are referred to Karuna Sadan as they do not accept them in their Balwadi. Children with Polio are sent to SEC day school at Antop Hill.

Appendix 9: Respondents Profile

The number of participants: 25. Information in alphabetical order is given below:

1. Key informant: Mr Javed Abidi, Programme Officer, Rajiv Gandhi Foundation, New Delhi.

Details of the Informant: Mr Abidi is an economist, writer and working for the Rajiv Gandhi Foundation set up in memory of Rajiv Gandhi the former Prime Minister. It is chaired by his widow Mrs Sonia Gandhi and has been doing good work in supporting various NGOs working in the field of disability. Mr Abidi uses a wheelchair, and has been working for the rights of disabled people. He was part of a group of people with disability who was responsible for having the Persons with Disability Bill passed through Parliament in 1994. He is known to be a very articulate activist for the disability group.

Venue: India International Centre, New Delhi.

2. Key Informant: Anupam Ahuja, Reader, NCERT, New Delhi.

Details of the Informant: Anupam is a special educator who represented the Indian situation at the Salamanca 'Education For All' Conference. She is a Reader at the NCERT and has had several years of teaching and research, with several publications to her name. She has worked closely with Professor Jangira on areas of Teacher Training and helped to implement into practice the Mel Ainscow / UNESCO Pack in several places during the PIED project. She is well informed about the ICDS and the wider reasons for excluding disabled children and has been in the field of special education for over a decade.

3. Key Informant: Professor Arora, Head of Teacher Training, NCERT, New Delhi.

Details about the Informant: Professor Arora had been in charge of the department of disabled children earlier before Neerja Shukla took over. He is a senior academic in NCERT.

4. Key Informant: Mr. Anil Bordia, Founder President: Lok Jumbish, Jaipur.

Details about the Informant: Mr Bordia was previously Secretary in the Ministry of HRD (Human Resource Development or Education). He was able to set up within 5 years of his retirement one of the best grassroots movements, similar in a way to the ICDS, dealing with primary education, through which movement he has set up systems of inclusion of disabled children. He operates in the districts and in the villages and has been able to develop an indigenous model involving the community called Lok Jumbish. He has the support of major International donors such as SIDA, ODA, UNESCO, UNICEF etc., as well as both the Central and State Governments, and having been in the powerful position of Secretary he has been able to network very successfully, both nationally and internationally.

5. Key Informant: Mr. Champak Chatterjee, Joint Secretary, Ministry of Human Resource Development, New Delhi.

Details about the Informant: Mr Chatterjee is a senior bureaucrat and is the present Joint Secretary in charge of Integrated Education in India as he heads the IEDC Department in the Ministry of HRD. He has been a writer and a journalist with an academic stint in Harvard.

6. Key Informant: (Mrs) Gowri Chatterjee, Joint Secretary, Ministry of Social Welfare, New Delhi.

Details of the Informant: Mrs. Chatterjee is a civil servant and is the Joint Secretary in the Government handling the work of the disabled and voluntary organisations in the Welfare Ministry. She is very well thought of and has recently joined the Ministry. Her husband is the Joint Secretary in charge of Integrated Education as mentioned above. We have a unique situation for the first time in India here, at present with a husband and wife team looking after the policies of the Government with regard to disabled children.

7. Key Informant: Professor Armaity Desai, Chairperson, University Grants Commission, Delhi.

Details about the Informant: Dr Armaity Desai is the Head of the University Grants Committee. She has been Head of the leading institute in the country for the Social Sciences, known as the Tata Institute of Social Sciences in Bombay. Researcher, Lecturer and Writer of numerous publications, books and journal, she is very well regarded in academic circles as a powerful thinker and is involved in social reform and research.

8. Key Informant: Mr. Gopal Dhutia, formerly Unicef Executive.

Details about the Informant: Mr Dhutia had been working with UNICEF for 22 years in the development field. He has had continuous dealings in the early days with ICDS Officials from Government of India during the policy formulation stage.

9. Key Informant: Mr. Rajmohan Gandhi, Centre for Policy Studies, Delhi.

Details about the Informant: Mr. Gandhi was a politician and a Member of Parliament in a previous Government. He is an eminent writer, author of biographies on some of

the national leaders such as Mahatma Gandhi, Sardar Patel, and C.R. Rajagopalachari. He is the grandson of Mahatma Gandhi. Known for his broad open views and deep insight into the nation's problems he is highly respected, internationally famed, and a well-known leader of India.

10. Key Informant: Mr. Bimal Jalan, currently, Governor, Reserve Bank of India, Bombay. Formerly Secretary, Planning Commission, New Delhi.

Details about the Informant: One of India's leading economists who has held several senior posts as Finance Secretary of India, Executive Director for India at the IMF and at the World Bank. Educated at Cambridge, Bimal is highly respected and has written several books on the Indian Economy and played a key role in shaping the economy with the policy formulation and implementations he has been involved with for twenty five years. His wife has been one of the founder members of the Spastics Society of Northern India and is a well known educationist and social reformer, who had worked under Professor Klaus Wedell for her Masters from the Institute of Education, University of London in the mid '70's. Bimal therefore has been closely involved with the work in the area of disability.

The interview was conducted in the garden of the Jalan Residence on a Sunday and Mr Jalan was relaxed and forthcoming.

11. Key Informant: Professor N K Jangira, World Bank, New Delhi.

Details about the Informant: Professor Jangira has been in charge of Teacher Education for Special Ed. Teachers at NCERT. Has done an Associateship at the Institute Of Education, London. Written several articles for international and national journals and is now working in the World Bank for the District Primary Education Programme set up by the Government of India towards universalisation.

12. Key Informant: (Mrs) Brinda Karat, General Secretary of the Federation for Women in India, New Delhi

Details about the Informant: Brinda is a noted activist on gender issues, and has been responsible for many changes that have taken place. She is also a senior politician

belonging to the CPM cadre. Highly articulate and a noted orator, she is very well respected for her work.

13. Key Informant: Ms Bika Karlekar, Centre for Womens Studies, New Delhi.

Details of the Informant: Bika is a sociologist from Oxford. She has been involved with research and training is also a noted academic and an activist working for gender issues. She has helped to set up the Centre for Womens Studies with some other noted stalwarts in the field. thinker, writer, and activist of a very strong group, Bika is well known for her forthrightness and her academic strength as well as her work in the field

14. Key Informant: Professor Vineeta Kaul, NCERT Early Childhood and Care, New Delhi.

Details of the Informant: Professor Kaul is a highly respected Senior Academic in charge of the whole area of early learning and preschool department of the NCERT. She is involved with training of teachers as well as research and works closely with the Ministry of Human Resources. She has written in several journals and publications at both National and International levels and given papers in various forums around India and abroad. She is also related to the Indira Gandhi family.

15. Key Informant: Professor Kuldeep Kumar, Head of Educational Research, NCERT, Delhi.

Details about the Informant: Professor Kumar is a psychologist, whose son had polio as a baby. He is a senior academic and deputy director level in NCERT. Involved in training of teachers and research.

16. Key Informant: Dr. Chitra Naik, Adviser Welfare and Education, Planning Commission, Yojana Bhavan, New Delhi.

Venue: Office of the Planning Commission, New Delhi.

Details of the Informant: Dr.Naik, is the wife of J.P Naik, India's most well revered educational analyst and author of several books on education. Dr Naik herself is a

policy maker in the Planning Commission and holds the position of Adviser, Education and Welfare. She has started several innovative schemes in the area of primary education in the rural and tribal areas and amongst the socially and culturally disadvantaged

17. Key Informant: Mr.Nani Palkhivala, Supreme Court Senior Advocate, Commonwealth, Nariman Point, Bombay.

Venue: The Office of Tatas, Bombay House, Bombay

Details about the Informant: Former Ambassador of India to the USA, regarded with high esteem, Mr. Palkhivala is one of the country's most respected Senior citizens. Known for his integrity, his spirituality, his nationalism, above all his exceptional mind, he is the country's top Constitutional Supreme Court Lawyer as well as one of the top industrialists heading one of the Tata (one of India's foremost Industrial houses) companies. He is also known for his financial analysis of the country's budget and each year talks before a packed audience of thousands of people. Thinker, philosopher, an outstanding writer and orator. It is indeed fortunate that I could get him to give me this interview, as these days he tends to be deeply depressed about the way the country is going. His wife is the Vice-Chairperson of the Spastics Society. He knows about our work with the disabled and about my present investigation.

18. Key Informant: Mr.R.S.Pandey, Joint Secretary, District Primary Education Programme, (DPEP) Ministry Of HRD (Human Resource Development), New Delhi

Details of Informant: A senior bureaucrat who has worked in the Ministry of Welfare and been the Joint Secretary looking after Disabled Welfare. He has written a book on the services provided by the Government, entitled and referred to in the thesis. He also worked for a while in the National Centre for Educational Research and Training (NCERT).

19. Key Informant: Dr Prodipto Roy, Senior Researcher, Indian Council of Social Development, New Delhi.

Details of the Informant: Dr. Roy has been in the field of social development doing research for over two decades and has a very sound knowledge of India's social structure and processes. He is the author of several books on the subject. He participated in several meetings regarding the formation of the ICDS and was a part of pilot studies before the delivery package was finally formulated. Together with the team of researchers he wrote the book about the genesis of the ICDS.

Venue: Offices of the Indian Council of Social Development

20. Key Informant: Binu Sen, Joint Secretary, ICDS, Department of Women and Child (WCD), Ministry Of Human Resource Development, Delhi.

Details about the Informant: A woman bureaucrat in charge of the ICDS programme, Government of India.

21. Key Informant: Professor Sharma, Director, NCERT, New Delhi.

Details of Informant: Professor Sharma is a senior academic with a background in Natural Sciences. He has been teaching and doing research for over three decades. He is Director of the National Council for Educational Research which is responsible for the National Curriculum, its evaluation, Teacher Training, Research and Evaluation. The NCERT is a premier autonomous body dealing with the educational status of the entire country and it functions as an arm of the Ministry of HRD (its counterpart in Britain would be the National Foundation of Educational Research).

22. Key Informant: Professor (Mrs) Neerja Shukla, Head of Department of Special Groups, NCERT, New Delhi.

Details about Informant: Neerja has done many years of work with the weaker sections and the vulnerable groups especially in the tribal areas. She is a senior academic heading the department looking after disabled children, training and research at NCERT.

23. Key Informant: Professor (Dr) B. N. Tandon, Head of Research and Monitoring Centre of ICDS, New Delhi.

Details about the Informant: Professor Tandon is one of the architects of ICDS. He is a leading physician as well as a surgeon, having just retired from the prestigious All India Institute Of Medical Sciences ... known to be the largest teaching hospitals in Asia with world wide contacts operating as an autonomous Institution under the Health Department. Professor Tandon is highly eminent, a man of great vision who has written several books and published several articles in national and international journals. He became Adviser to ICDS in the very early stages and is regarded as one of the founder members of the ICDS.

The Venue: Two meetings took place. I had sent my papers to him earlier to give him time to read them before we met. Initially Dr Tandon was rather annoyed with my research question. The first meeting took place in his office. He had called in a senior doctor in the ICDS programme to support his views.

The second meeting took place in the canteen of the Hospital that Professor Tandon is now heading where he had invited me for lunch. Again he had invited another person to join us. This was Dr Verma, an Orthopaedic Doctor who had been in charge of the Rehab Unit of the AIIMS and had recently retired. Very well experienced in the workings of the Govt. and disability issues, he made a few comments at the end of the interview.

24. Key informant: Professor Verghese, National Institute of Educational Planning, New Delhi.

Details about the Informant: A senior academic researcher involved in field research on educational difficulties and management problems in the urban and rural areas.

25. Key Informant: Professor Anita Verma, Head of Department of Child Development and Gender Studies, M. S. Baroda University, Baroda.

Details of Informant: Professor Verma is the Head of the Department of Child Development and Women Studies, an eminent national and International authority on Child Development and Gender Issues in India. She has written a number of books and publications and several on preschool activities including the ICDS. She also got her Masters degree from the Institute of Education, University of London.

Appendix 10: Curriculum of the National Institutions

The National Institutes run by the Government of India, have their main goal in training of professionals. Degree courses are conducted for teachers and certificate courses for junior educators with high school certificates. Short-term refresher courses are conducted for clinicians and educators. Workshops, seminars and symposia are organised for professionals and parents.

The National Institutes provide diagnostic and therapeutic services with the view to give practical training to professionals. The data generated is used for research.

Following are the objectives of the National Institute:

- evaluation
- prescription of aids and appliances
- repairs of aids
- therapy
- assessments
- psychotherapy,
- play therapy and social work support
- neurological evaluation
- referral

Awareness campaigns mainly consist of seminars and workshops.

Appendix 11: Photographs

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1. A student in the Spastics Society of India school exhibiting her pottery

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2. Children in Karuna Sadan, new demonstration model of integration in Dharavi

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PICTURE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES

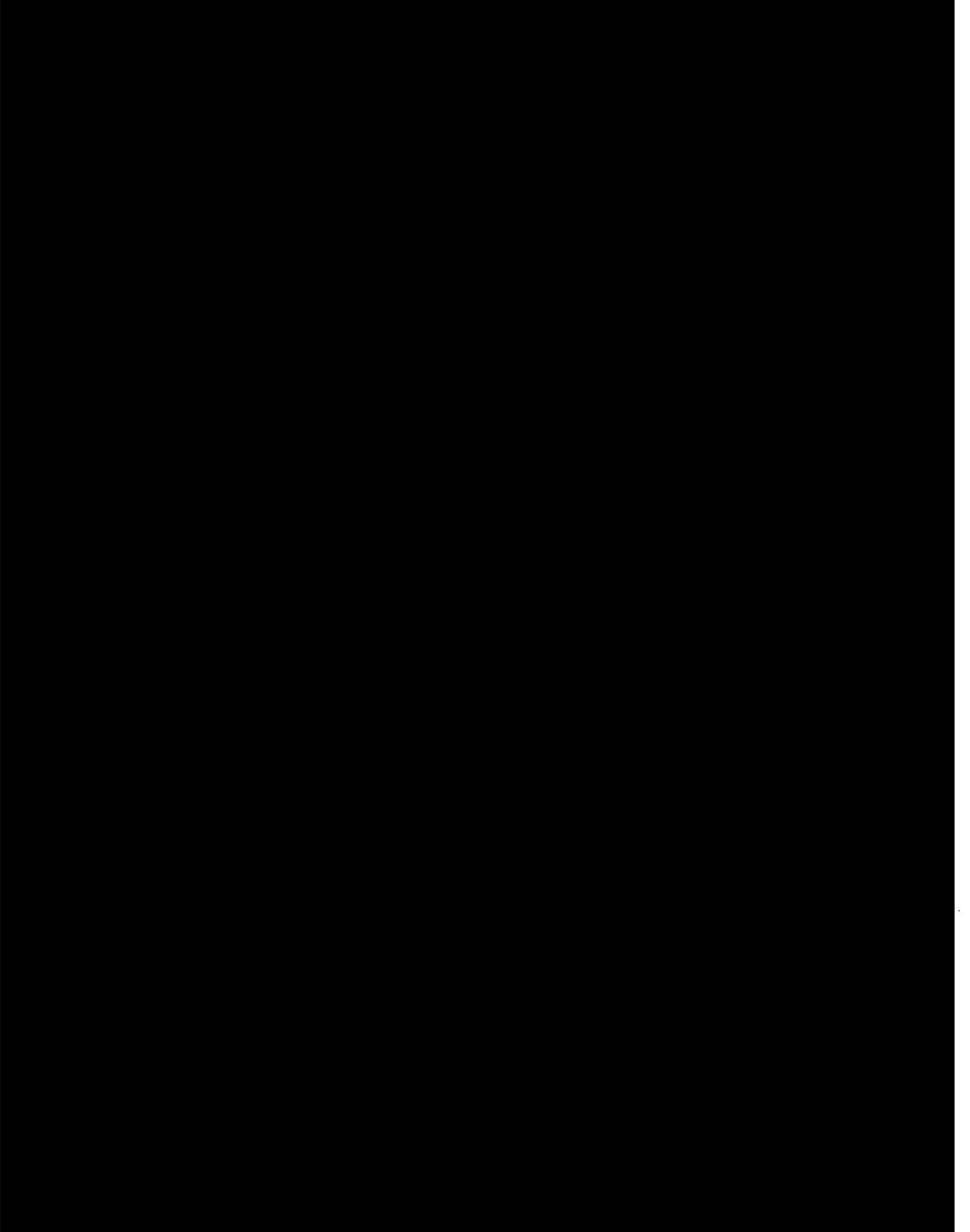
Children arriving in the School Bus.

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7. Dharavi in the monsoon.

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11. All anganwadi in progress.

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12. Mother and disabled child

